UNDERSTANDING CAREGIVERS OF NATIVE HAWAIIAN KŪPUNA WITH AGE-RELATED MEMORY LOSS ON ONE HAWAIIAN HOMESTEAD

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Dedication

Auntie Brenda, I dedicate this work to you…
your journey into the unknown of Dementia has taught me
about caring for those who care for us as you experienced the
challenges of aging with caregivers wanting to ensure you
age with dignity and grace.

Mahalo to the Kekauoha ʻohana
for allowing me to share this intimate time of aging
that has allowed me to see how caregivers and care recipients are challenged.
Most importantly, how an ʻohana
can come together and care for a most treasured member
when they are have learned from the care recipient how to do
everything in love.
You set the standard of your care with the love you provided through the years.
Many can learn from your example.
I have witnessed caregiving at its finest through the love and care
provided through the caring hands and hearts of Puni, Kaapuni, Jeremiah, the
support team to Uncle Hale.

I thank my ancestors for paving the way, providing a heart of service
The love of God helps us endure…

I dedicate my lessons learned to…

Brenda Kahelekaapuni Kekauoha

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This journey has not been the easiest, but through the grace of God I made it through. Mahalo to all, God chose to journey with me and become part of this story. I thank the kūpuna of Papakōlea here and gone for all that they planted. The community of Papakōlea for sharing their story and becoming a part of mine, You are honored, forever thankful for all provided.

Then there is my family and my village; there are none better. You are one and the same. My mom, always there, my sister Renee, who held my hand, my love, Thomas who never let me fall or think I could fail. My sistahs, Puni, Theone, and Lilia you brought me to this place of excellence to dwell and held me up and let me soar. Those who are from Kula no na Po'e Hawaii and the Papakōlea Community Center.

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ABSTRACT

Understanding the concerns and challenges of caregivers of Native Hawaiian kūpuna or elders (age 55 years and older) with age-related memory loss conditions, specifically, Alzheimer's Disease and Related Dementia (ADRD), on one Hawaiian Homestead is the focus of this doctoral research study. ADRD is known to affect memory, thinking, and behavior. This research is grounded in Community-Based Participatory Research (CBPR) principles and utilizes a mixed methods strategy to assess the needs and concerns of caregivers.

This mixed methods study utilizes a quantitative arm of the study involving development and administration of a written survey eliciting sociodemographic characteristics, as well as knowledge-attitudes-behaviors on caregiving. The qualitative arm of the study is with focus groups intended to clarify and extend information learned through survey data. Study findings can assist a homestead community in determining the types of resources and support essential for long-term care to mitigate caregiver burnout and simultaneously provide services that enhance kūpuna care. Results will inform providing safe, compassionate, community-based culturally appropriate care in the community for kūpuna who prefer to age in place.

This dissertation research aligns with the focus of social welfare on health equity and cultural competence focusing on Native Hawaiians, a marginalized population and the need to provide relevant ADRD services for all. Further, this research contributes to the growing literature on aging in place from an Indigenous (Native Hawaiian) cultural perspective. This research underscores the importance of community "self"-determination. Specifically, study results indicate the cultural preference is caring for kūpuna is a community kuleana (responsibility). By extension, there is a need for community training that strengthens the capacity to address this kuleana. Current and emerging community leaders from across the generational continuum would benefit from training that ensures community participation in identifying moreover, addressing kūpuna needs, as served in a spirit of caring and excellence. Findings from this study are community-specific and

cannot be generalized to all Native Hawaiians and Native Hawaiian communities. Research performed in one urban homestead community may provide critical considerations for others interested in developing policy and research for/with elders and family caregivers in the context of ADRD.

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CHAPTER 1. LITERATURE REVIEW

Understanding the concerns and challenges of caregivers of Native Hawaiian kūpuna or elders (age 55 years and older) with age-related memory loss conditions, specifically, Alzheimer's Disease and Related Dementia (ADRD), on one Hawaiian Homestead is the focus of this doctoral research study. ADRD is known to affect memory, thinking, and behavior. As the disease progresses, a kūpuna may have difficulty recognizing family members, wander off and not remember how to return home, have trouble speaking, reading, or writing, and have difficulty remembering how to perform basic self-care. The Alzheimer's Association (2018) projected there are approximately 28,000 elders age 65 and in older with ADRD in Hawai'i with a projected 25% increase to 35,000 between 2018- 2025.

The literature on caregiving in the context of ADRD indicates that caregivers often are concerned about the safety of their elders in the home and community environment and often wonder if they are "doing enough" to care for their loved one. A caregiver is someone who provides care to a person in need of assistance with Activities of Daily Living, or everyday tasks such as self-care and personal hygiene (Centers for Disease Control, 2015). Caregiver challenges increase as the disease progresses. The three primary reasons caregivers provide care and assistance to a person with ADRD are the desire to keep a family member or friend at home (65%); proximity to the person with dementia (48%); and the caregiver's perceived obligation as a spouse or partner (38%) (Alzheimer's Association, 2018). There is an expectancy that there will be a positive correlation between knowledge and resources available moreover, caregivers' perception of need.

Statement of the Problem. The effects of being a family caregiver, though sometimes positive, are overwhelmingly negative, with high rates of burden and psychological morbidity as well as social isolation, physical ill health, and financial hardship (Brodaty & Donkin, 2009). Caregivers put their lives on hold to care for loved ones with

memory loss. Family caregivers of individuals with ADRD become the second patient due to the stress, and they may even experience illness while providing care despite being critical to the quality of life for the one with ADRD. Stigma and negative community attitudes are common toward dementia despite the high prevalence of dementia (McCloskey et al., 2017). Individuals with ADRD experience multiple symptoms that change over a period of years. The pace at which symptoms advance from mild to moderate to severe varies from person to person (Alzheimer's Association, 2018).

Current and former caregivers are the focus of this research due to the concerning health statistics of kūpuna and the steady increase of the aging population worldwide and in Papakōlea. Former caregivers were included in this study because those who have lost loved ones from the targeted illnesses have valuable information to share about their journey, in regards to the challenges and successes experienced. Therefore, this study captured historical caregiving experiences to support future caregivers. Individuals with dementia living in the community are more likely than older adults without dementia to rely on family members for care and assistance (Alzheimer's Association, 2018). The sharing of caregiving experiences is beneficial (how so? elaborate from caregivers' perspective), and can counter the perceived sense of isolation and provide supportive lessons for caregiver).

The focus of this dissertation research is on Alzheimer's disease because it is the most prevalent form of dementia in the U.S., Hawai'i, and the kūpuna receiving community care on one Hawaiian Homestead. Community-based participatory research (CBPR) method was utilized with consideration of the community of Papakōlea's prior experience with research and their expectations in research to advance community capacity and wellness.

The quantitative arm of the study involved the development and administration of a written survey eliciting socio-demographic information, as well as, knowledge- attitudes-behaviors on caregiving. The variables of interest were demographics of caregivers and care recipients, patterns of caregiving, and what resources are available to support their caregiving efforts and data analysis included descriptive statistics and analysis of variance. The qualitative arm of the study involved focus groups with goals to achieve clarity and extend information learned through survey data. Specifically, focus groups elicited participants' caregiving experience in the context of ADRD. This mixed methods strategy was viewed as optimal for understanding the complex dynamics of ADRD, caregiving, and the community at the nexus of Native Hawaiian culture.

Findings from this research underscore the importance of community "self"-determination. Specifically, study results indicate the cultural preference when caring for kūpuna is a community kuleana (responsibility) (Browne et al., 2014).

Aging Population. In 2015, people age 65 and older represented 14.9% of the total population in the United States (Alzheimer's Association, 2015). There was a 1.6 million increase in this population from 2014 to 2015 (Centers for Disease Control and Prevention, 2015). Today, about 5.2 million U.S. residents are full, or part Native American or Alaska Natives and another 527,077 are full or part Native Hawaiians (Braun & LaCounte, 2015; U.S. Census Bureau, 2013).

The U.S. native peoples experience continued disparities in health many of which are risk factors among the aged population for dementia; the number and proportion of indigenous elders (Native Indians, Alaska Natives, and Native Hawaiians) have grown. Today, there are 36 homestead communities statewide. The 2010 Census reports 355,816 Native Hawaiians are residing among the over 1.2 million individuals in the state of Hawai'i. In 2010 there were 16,062 residents of Hawaiian Home Lands on the island of O'ahu with 4011 (25%) age 45 and older. (State of Hawai'i Data Book, 2010).

The fast increase in the aging population is cause for concern for caregivers needing

to understand the impact of diseases that occur in aging such as dementia. According to the United States Census Bureau (2017), there will soon be more older people than children in the world, and the older people will be at an extreme old age (≥ 85). The "oldest old," those aged 85 and over, are the most rapidly growing elderly age group. Additionally, the impact of the baby boomers who began turning 65 in 2011 is causing a unique demographic transition to occur worldwide. Residents age 65 and older grew from 35.0 million in 2000 to 49.2 million in 2016, accounting for 12.4 percent and 15.2 percent of the total population, respectively (U.S. Census Bureau, 2017).

According to the 2010-2015 U.S. Census, American Community Survey there are 457 people aged 55 and older representing approximately 25% of the total population of Papakōlea, Native Hawaiian Homestead on the Island of O'ahu. These type of health statistics for Native Hawaiian kūpuna indicate a need to support managing their care to ensure acceptability and accessibility of services. When accessing or receiving supportive services at the community level, many of the barriers existing in the current medical model are addressed such as the full range of factors that contribute to disparities, including social and environmental factors that extend beyond the health care system (Artiga, Foutz, Cornachione, Garfield, 2016).

More needs to be understood about people diagnosed with ADRD. Many may forego diagnosis due to the concerns of what happens when they have been diagnosed, the changes in lifestyle that begin with limitations on day to day activities of daily living imposed by family. If diagnosed, the stigma and delays in sharing the diagnosis with family members. Dementia is often not recognized and diagnosed in the private practice setting. Primary care physicians are thought to be poor at diagnosing ADRD for Asian Americans of Honolulu aged 65 years and older attending an internal medicine private group practice because they have not been trained to accurately diagnose this condition (Valcour, Masaki, Curb, & Blanchette, 2000). For many reasons, it is difficult to ascertain precisely how many

Native Hawaiians kūpuna have been diagnosed with ADRD in Papakōlea.

> As the aging population increases, it is imperative that research studies aim to understand how to alleviate the additional burden and stress on families, especially those responsible for primary and secondary caregiving and among Indigenous populations. The increase in aging is causing many caregivers to need to access support and respite services because many families have not had enough education on ADRD. As loved ones fail to recognize family members as the disease progresses, cognitive and functional abilities decline, the rate which symptoms advance from mild to moderate to severe varies from person to person, one ultimately becomes bed-bound and needing around the clock care; and will need care until death (Alzheimer's Association, 2016).

Dementia. Dementia is one of the leading causes of disability and institutionalization in older people posing a severe threat to public health and the social and economic development of modern society (Mangialasche, Kivipelto, Solomon, & Fratiglioni, 2012). Dementia is a complex human syndrome that affects the brain in three areas: language, memory, and decision-making, thus, causing significant challenges for individuals to perform necessary activities of daily living. The latest edition of the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; DSM-IV-TR; American Psychiatric Association, 2000), classifies dementia as a neurocognitive disorder that is either major or mild. A major neurocognitive disorder has evidence of a significant cognitive decline that interferes with independence in everyday activities (e.g., assistance may be needed for more complex activities such as paying bills or managing medications). The cognitive decline with a mild diagnosis does not interfere with everyday activities.

Different causes of dementia are associated with distinct symptom patterns and brain abnormalities. Dementia is categorized into a few subtypes according to its causes (Alzheimer's Association, 2018). There are many known types of dementia such as Alzheimer's disease (ADRD) and other related conditions (i.e., vascular dementia,

Parkinson's disease) associated with older age of particular concern for the aging population with significant age-related memory loss (see Appendix B), that is not easily diagnosed which causes late intervention and treatment (Nall & Legg, 2017). ADRD is the most common neurodegenerative disorder. What is of further concern is the growing number of cases of younger onset, before the age of 65. The likelihood of developing dementia roughly doubles every five years after the age of 65 (Alzheimer's Association, 2010).

Alzheimer's accounts for about half of the affected population, followed by vascular dementia (VaD) (20–25%), mixed dementia (5–10%), Parkinson's disease, dementia with Lewy bodies, physical brain injury, Huntington's disease, Creutzfeldt–Jacob disease, frontotemporal dementia/Pick's disease, normal pressure hydrocephalus and other less encountered types of dementia (Chen, Lin, & Chen, 2009).

There are an estimated 5.5 million individuals in the U.S. accounting for 60 to 80 percent of dementia cases. By 2040, the number of dementia cases worldwide is estimated to increase to 80-110 million (Sentell et al., 2015). Those not in the labor force are increasing the old age dependency ratio for those 65 and older (Colby & Ortman, 2014). By 2030, one in five Americans is projected to be 65 and older; by 2044, more than half of all Americans are expected to belong to a minority group (Colby & Ortman, 2015). We are just beginning to comprehend the impacts at the national and local levels of the population of elderly and the length of life increase (World Health Organization, 2014; National Institute on Aging, 2017). The diagnosing and reporting systems used to track dementia are not standardized causing varying prevalence estimates internationally (Alzheimer's Association, 2010). The exact numbers of those who have been diagnosed with dementia are unknown.

Change occurs in the community when others understand the challenges of family, friends, and neighbors and offers support. Despite the high prevalence of dementia, negative community attitudes and stigma towards dementia are still common (Kim & Mortby, 2017). People with dementia and their caregivers are often isolated due to the

stigma attached to the disease. The three domains of stigma of AD include (public avoidance, pity, shame) and their roles in the intention, attitude, subjective norm, and perceived behavioral control regarding care-seeking from primary care physician (PCP) and AD specialists (Casado, Hong, & Lee, 2018).

Beliefs about the stigma of pity were most prominent, followed by the stigma of public avoidance and shame, men report significantly higher levels of stigma than women (Casado, 2017). Stigma can also discourage people from seeking health services resulting in the delayed diagnosis and timely treatment of dementia (Kim & Casado, 2017). One of the most necessary actions to contribute to the prevention of the threats mentioned is the development of dementia literacy (Low & Anstey, 2009). Promoting dementia literacy supports everyone in a community with their understanding of what dementia is and how it affects people. (Dementia Friendly America, 2015).

The causes of dementia can vary and depends on the types of brain changes that are taking place (National Institute on Aging, 2016). An estimated 5.3 million Americans of all ages had Alzheimer's disease in 2015 (Alzheimer's Association, 2015). This number includes an estimated 5.1 million people age 65 and older and approximately 200,000 individuals under age 65 who have younger-onset (Alzheimer's Association, 2015; National Institute of Aging, 2016). Economic consequences have been observed with payments towards health care costs estimating to be $226 billion in 2015 (Alzheimer's Association, 2015).

People with dementia, their families, and friends are affected on personal, emotional, financial, and social levels. The societal cost of dementia is already enormous significantly affecting every health and social care systems in the world. A proper understanding of the societal costs of dementia, and how these have an impact on families, health, social care services, and governments causes a problem (Alzheimer's Association, 2010). The increase in the elderly population causes anticipation of the challenges of aging such as worsening health and social dependency.

According to the Alzheimer's Association in Hawai'i (2016), approximately 8.9% of those age 45 years and over report they are experiencing confusion or memory loss that is happening more often or is getting worse. Many caregivers feel that there are adverse reactions to the term dementia, and are concerned others would associate it with being 'demented.' As the disease progresses, the possibility of institutionalization may become physically necessary. In Hawai'i, 77% of caregivers are aged 45 and over (Alzheimer's Association, 2016). According to the current caregiver survey administered in Papakōlea, 45% of the people receiving care have been diagnosed with ADRD with the two largest groups receiving care are parents/ parents-in-law and grandparents. The community has many multi-generational homes, 59% of caregivers reside with 51% kūpuna providing personal care such as feeding, dressing, and bathing.

The economic impact on families is not entirely understood. Recently, when the staff of Kula inquired about the cost of placement of a kūpuna at one of the local nursing homes, $55,000, was the deposit needed from the family for the first two years. Additionally, to qualify for Medicaid, there would need to be a spend-down of assets. The kūpuna might be eligible for a scholarship to cover costs in two years after admittance.

Alzheimer's disease (AD). Alzheimer's disease was first described in 1906 and is now used only in those instances that refer to the underlying disease or the entire continuum of the disease (Alzheimer's Association, 2017). The term Alzheimer's dementia is used to describe the dementia stage of the continuum (Alzheimer's Association, 2018). Individuals with Alzheimer's dementia experience multiple symptoms that change over a period of years. In 2015 there were 26,000 Hawai'i residents diagnosed with of ADRD. In Hawaii, this number was expected to grow to 35,000, by 2025, an increase of 34.6% (Yuan, Karel & Yuen, 2017). These figures do not include those who are undiagnosed or younger than 65.

In Hawai'i, preparation is underway for this public health crisis. People in the final stage of the disease are bed bound requiring round the clock care, and the disease is

ultimately fatal (Artiga, et al., 2016). The most prevalent form of dementia is one of many different types of dementia affecting Hawaii communities as well as other related conditions associated with older age is of particular concern. Services are in demand for the aging population with significant memory loss due to crossing a span from undiagnosed to dementias that affect cognitive functioning (Alzheimer's Association, 2018).

Risk Factors. Type 2 diabetes is a significant public health problem experienced among ethnic minorities including Native Hawaiians, and that has been shown to be a significant risk factor for ADRD and other forms of cognitive decline (Look, Trask-Batti, Agres, Mau, & Kaholokula, 2013). Hypoglycemic episodes severe enough to require hospitalization or an ED visit are associated with increased risk of dementia, particularly for patients who have a history of multiple episodes. In 2009, a research study observed a 2.39% increase in absolute risk of dementia per year of follow-up for patients with a history of hypoglycemia, compared with patients without a history (Whitmer, Karter, Yaffe, Quesenberry, & Selby, 2009). Native Hawaiians have prevalence rates 2 – 3 times higher than the national average. Modifiable risk factors and treatment of these risk factors could potentially decrease the dementia burden in Native Hawaiians. Given the high rates of type 2 diabetes in the Native Hawaiian population, there needs to be increased knowledge and awareness of ADRD and dementia for Native Hawaiians (Look, et al., 2013).

Stigma around Alzheimer's disease exists in part due to the lack of public awareness and understanding of the condition. Stigma may add to the burden of Alzheimer's disease as it can prevent individuals from seeking services (Centers for Disease Control and Prevention, 2015). Health literacy can help to remove some stigma associated with this disease. Although growing, training on what is involved with ADRD is limited and often not sought until families are overwhelmed.

Exposures to multiple factors experienced over the lifespan determine the risk of dementia in later life (Mangialasche, et al., 2012). The memory problems, misunderstandings, and behavior typical in the early and intermediate stages are often

attributed to normal effects of aging, accepted as personality traits, or just ignored. Many cases remain undiagnosed even in the intermediate, more serious stages until an inpatient admission is necessary (National Institute on Aging, 2010).

ADRD among Native Hawaiians is severely understudied, strong evidence exists about dementia prevalence in Japanese-Americans in Hawai'i and other Asian American subgroups are understudied and, to our knowledge, there are no population-level prevalence studies on dementia for Native Hawaiians (Sentell et al., 2015). It is not clear if these higher rates of patients hospitalized with dementia are related to higher underlying dementia risk or different health care access, cultural or caregiving factors, and other explanatory factors (Casado, Hong, & Lee, 2018). The higher rates of ADRD might be related to the higher rates of cardiovascular disease, obesity, and diabetes among Native Hawaiians (Sentell et al., 2015).

Caregiving. The number of caregivers is increasing for people with dementia who eventually need constant care and help with the most basic activities of daily living (ADL), creating a substantial economic and social burden (National Institute on Aging, 2017). Because of the higher prevalence of cardiovascular disease, obesity, hypertension, and diabetes among Native Hawaiians this population would be more likely to have hospitalizations with a dementia diagnosis compared to other racial/ethnic populations (Sentell et al., 2015).

As the number of seniors aging in Hawai'i rapidly increases, Hawaii faces limited capacity in its residential care homes. With only 4,200 beds in nursing homes and 7,000 spaces in residential facilities in 2010, home care will need to be a viable option (Hawai'i Community Foundation, 2013). Hawai'i's current facilities would be able to serve only 30% of the 38,000 older adults projected to need long-term care in 2035 (Hawai'i Community Foundation, 2013). According to research the use and costs of health services varies by race/ethnicity in the U.S. Expensive inpatient care for dementia show higher rates for African Americans compared to Whites. Native Hawaiians are one of the top two fastest-

growing racial/ethnic groups in dementia in the U.S. with almost nothing known about prevalence, and consequences of dementia in this population. The majority of work in racial/ethnic disparities in dementia has focused on African Americans and Latinos. (Sentell et al., 2015).

> Native Hawaiians, the dominant ethnic group in Papakōlea, are known to have a high incidence of some cancers, diabetes, hypertension and several other debilitating chronic illnesses. They are more likely to report behavioral health risks, such as smoking, live within/below 100%–199% of the poverty level, and find cost a barrier to seeking care when compared with the State's other major ethnic groups of the same age, Americans of Chinese, Japanese, and Filipino ancestry (Browne, Ka'opua, Jervis, Alboroto, & Trockman, 2016; Ka'opua et al., 2011).

Native Hawaiians have health disparities across a variety of health outcomes. For instance, Native Hawaiians experience higher preventable hospitalizations for chronic conditions and are disproportionately more likely than other racial/ ethnic groups to be hospitalized for a dementia diagnosis across multiple age groups. The higher rates of Native Hawaiian inpatients with dementia are also coupled with younger ages for those hospitalizations (Sentell et al., 2015). The need for long-term care comes at the time when there are some unexpected life changes. Many have not given thought or time to prepare for how life will differ when faced with the change in socio-economic status that for many come with retirement coupled with a possible declining of mental and physical health that precedes an imminent need of caregiving.

Caregivers need to be provided the tools to help them cope with all situations. Coping refers to the actions that people take on their behalf as they attempt to lessen the impact of life problems when dealing with stressful situations (Pearlin and Schooler, 1978). It is due to the progressive impairments endured by family members who find that their responsibilities and demands have expanded over time (Pearlin, Mullan, Semple, & Skaff, 1990). Caregivers are impacted by the same chronic stressors associated with health

disparities such as dementia care recipients which include perceived discrimination, neighborhood stress, daily stress, family stress, acculturative stress, environmental stress, and maternal stress (Djuric et al. 2008).

There are kūpuna receiving community support assistance including respite time which is needed. Many families continue to reach out to the staff at the Papakōlea Community Center when they are in crisis. The later the notification to community caregiving is being provided for a kūpuna makes it harder for resources and support to be provided at their time of greatest need. It is, for this reason, that information on ADRD is needed before families are trying to navigate the healthcare system and at the onset of the condition. Additionally, kūpuna are safer when they begin to wander when community members have been made aware and can alert the family when one seems lost.

What we know about Native Hawaiian dementia caregivers is limited. This limited knowledge causes a great need to understand resources and support required because dementia may affect the family for years. More than one in four dementia caregivers are in the "sandwich generation" caring for both someone with dementia and a child or grandchild (National Institute on Aging, 2016). The care is provided without an understanding of how to provide adequate care; many caregivers experience a sense of guilt that they are providing inadequate care for their kūpuna (Biegel & Schulz, 1999).

The years that one can provide caregiving for a loved one with dementia or other related conditions can lead to caregiver illness, depression, stress, and anxiety. However, many families are unable to follow-through with long-term placement for cultural, financial, and other reasons. It has been said that it takes a village to raise a child and now it seems as it takes a village to keep a caregiver and kūpuna safe during the stages of ADRD.

Native Hawaiians. First to discover the 1500 mile Hawaiian archipelago in the Pacific Ocean, Native Hawaiians, migrated to Hawaii using advanced sea navigation skills (Kana'iaupuni & Malone, 2006). The Native Hawaiian people are a distinct and unique indigenous group with a historical continuity to the original inhabitants of the Hawaiian

archipelago whose society was organized as a Nation before the arrival of the first non-indigenous people in 1778 (Library of Congress, 2000). Hawaiian or Native Hawaiian is someone of Hawaiian ancestry. Other terms, Kanaka Maoli (real or true people), Kanaka ʻŌiwi (bone people), or ʻŌiwi Maoli (true bone) are communities today to emphasize Hawaiian indigeneity (Kauanui & Kauanui, 2008).

Indigenous communities historically have been victims of the massive dispossession that removed native people from their ancestral lands and took away their language, culture, and labor resulting in significant damage in health, educational levels, and in social well-being for their populations, including Native Hawaiians (Bird, 2007). The changes as a result of the overthrow were devastating for a society that emphasized a deep relationship with the land and sea, rather than with the market economy that dominated life in Europe and the United States (Department of Hawaiian Home Lands, 2002).

The disparity in the health status of Native Hawaiians when compared to other ethnic populations in Hawaiʻi and across the Continental United States continues to be of concern and an area for increased research. Native Hawaiian and other indigenous health researchers consistently emphasize the influence of historical trauma and systematic discrimination and inter-generational marginalization on current health disparities (Kaholokula et al. 2009; Ka'opua 2008; Mokuau 2011).

Any effort to address Native Hawaiian health disparities must be grounded in an understanding of the historical past and ongoing impact of colonization of the Kingdom of Hawai'i by the United States. Before the HHCA, Hawaiian identity was based on kinship, social class, genealogical ties-by birth or hānai-birthplace, ability, achievement, and māna (power). After 1919, the law defined a Hawaiian by blood quantum or race. (McDermott & Andrade, 2011). The United States began the takeover of the archipelago beginning with missionary entry in the 1820s and culminating first in the overthrow of Queen Lili'uokalani and then the Newlands Act of Incorporation placing Hawaiian land under the control of colonial power (Schachter, 2016).

This devastating past is considered as an essential component to understanding the troubling socioeconomic and health status of this population today. Homestead land was intended for reparations for the overthrow of the Hawaiian Monarch and the loss of land during the Great Mahele of 1848 (Trask, 1991). Ancient Hawaiians lived in harmony and balance with spirits, nature, and every alternative. They passed knowledge on by oral tradition, and have rules within the type of kapus (that promote cleanliness and order); resolved psychological and social conflicts with ho'oponopono (a variety of family group therapy).

Health was outlined as possession of a strong sacred living force referred to as māna that has to be kept pono or in harmony and lokahi or unity with the universe. Hawaiian health was always māna, pono, and lokahi. Sickness could be related to negative thoughts or words from another or oneself, and kahunas used this to their advantage to facilitate healing. (Hope & Harbottle Hope, 2003). Cultural knowledge and cultural practices are the ways of knowing that lead to physical healing, psychological health, conflict resolution, interpersonal problem-solving, family relationships, community building, spiritual healing, and general well-being (McCubbin & Marsella, 2009).

Despite severe and massive challenges wrought by historical and cultural trauma, the endurance of Native Hawaiians in the 21st century speaks to their cultural resiliency. Resiliency is the ability to deal successfully with significant adversity or risk and focuses on protective and recovery factors in health (Browne, Mokuau, & Braun, 2009).
Hawaiian well-being is deeply rooted in a connection to their land and culture. This connection can be found in Papakōlea. At the core of this profound connection is the deep and enduring sentiment of aloha ʻāina or love for the land. The fundamental expression of the Hawaiian experience is Aloha ʻāina which represents identity, continuity, and well-being as a people is sustained in the ʻāina (Kikiloi, 2010).

Historical/Cultural Trauma. Historical and cultural trauma, a result of forced colonization, has been linked to ongoing socioeconomic marginalization and present-day

health disparities in Native populations (Sotero, 2006).

> Communities are influenced by their indigenous populations' histories and varied tribal and family affiliations rich in cultural diversity with individuals and, linguistic traditions, geographies (reservation, homestead, rural or urban dwelling). Traditional Native and the majority of American cultures care preferences may fall at any point along a broad spectrum of engagement (Browne, et al., 2016; Verney, 2015; Mokuau, 2011).

When addressing the disparate conditions of indigenous populations and people of color one include the impact of historical and cultural trauma theories. The trauma suffered at the hands of others throughout history has modern-day repercussions that are seen in a number of ways. When members of a collectivity feel they have been subjected to a horrendous event that leaves indelible marks upon their group consciousness, theories of historical and cultural trauma are suggested. Memories and changing their future identity in fundamental and irrevocable ways transmitted from one generation to the next marking the impact of trauma (Alexander et al. 2004; Anderson 2008; BraveHeart 2011).

Historical trauma (HT) is defined as cumulative emotional and psychological wounding across generations, including the lifespan, which emanates from massive group trauma (Brave Heart, Chase, Elkins, & Altschul, 2011). The result of "historical trauma," is experienced on an individual and collective level and is transmitted from one generation to the next. Hawaiians who have suffered collective depression, a change in subsistence practices caused economic deprivation, population decline from introduced diseases, land alienation and urban relocation, religious suppression and cultural repression, political overthrow and marginalization are resulting in the loss of self-concept (Brave Heart, 2011).

The theoretical underpinning to health disparities is believed to be partly due to "cultural wounding" resulting in communal feelings of disruption and a sense of collective

helplessness, which can, in turn, impact one's "sense of self" and health-seeking behaviors (Mau, 2010).

Papakōlea. Papakōlea is the only community to be chosen for Hawaiian Homestead by Native Hawaiians, as opposed to being assigned by the U.S. government. It is comprised of three subdivisions: Papakōlea (1934); Kewalo (circa 1954), and Kalāwahine. Papakōlea is a Native Hawaiian homestead community in the city of Honolulu, located on the island of O'ahu. This settlement was established in 1934, as an amendment to the Hawaiian Homes Commission Act of 1921, before Hawai'i became a State. Papakōlea covers 177 acres and is the only Hawaiian homestead in the city of Honolulu with an urban location, out of 36 homesteads in Hawai'i statewide. Papakōlea has a long history of struggles and victories, which continue today.

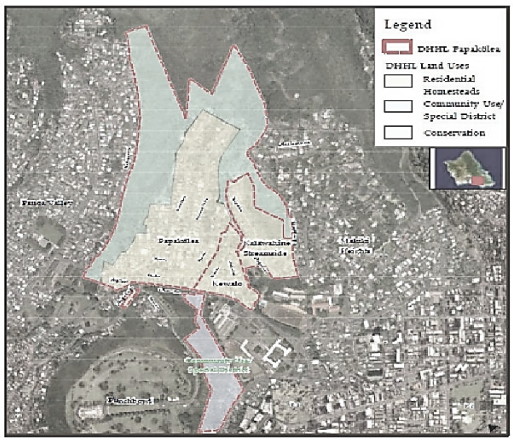

Figure 1. Map of the Papakōlea Residential Communities DHHL 2009 Papakōlea Regional Plan

The original settlers of Papakōlea were deemed squatters who relocated from[1] agricultural lands after the Great Mahele when Hawaiians were forced from their homes allowing foreigners to purchase property (Trask, 1992). This residential community can trace its origin to land tenure struggles of the late 1800s. Many Hawaiians, displaced from their rural lands and in response to the squalor of the downtown tenements, chose to settle on public lands mountainside of downtown to regain some of the healthy self-sufficient lifestyles they had known in the countryside. Although they had successfully created a vibrant community, the residents had no legal rights to the land they occupied. (Schacter, 2016).

In 1923, when Papakōlea residents were faced with the threat of being removed from the land they had settled on by a government sale, the community both Hawaiian and non-Hawaiians, joined to stop the sale and to ensure there would be no further threats by lobbying to become a homestead. Many of the Native Hawaiian families living in the community wisely saw this as a vehicle to gain legal ownership (Schachter, 2016). On May

16, 1934, after many years of lobbying, the Congress of the United States of America amended the Homestead Act to include the areas of Auwaiolimu, Kewalo, and Kalāwahine, known as Papakōlea, as Hawaiian Home Lands under the Hawaiian Homes Commission Act of 1920.

As a result of the historical struggles, residents emphasize acknowledging and supporting the kūpuna who led the lobbying for this land to be included in the HHCA of 1920 in 1934 (Dillard, 2008). In Native Hawaiian communities, it is culturally appropriate to care and support kūpuna that wish to age in place. However, families have voiced concern that they are not equipped to provide their kūpuna with quality care to "age in place." It is imperative that families be provided the tools needed to provide care for their treasured kūpuna in their homes and community.

There is no individual land ownership of Hawaiian Homestead lands. The land is held in federal trust that was established by the Hawaiian Homes Commission Act of 1921. The State of Hawai'i, Department of Hawaiian Home Lands, administers that "land trust," providing initial 99-year residential leases to qualified Native Hawaiians. Papakōlea is the only homestead community that was occupied before its homestead identity. This designation came after decades of unrelenting efforts by Hawaiian settlers to secure their land. The residents were given 99-year leases under the Homestead Act, and the individuals began to build permanent homes after this. Most homes in Papakōlea were constructed in the 1950s. These 'squatters' [2] developed roots and created the first neighborhood of Papakōlea and Kalāwahine (Schachter, 2016).

According to the 2010 U.S. Census, approximately 1,795 people are living in Papakōlea, and 306 people out of the total 457 aged 55 and older across locations reside in Papakōlea. The median household income of $52,167 is comparable to that of the City and County of Honolulu as a whole ($51,914). Although the income looks promising, 60% of the households fall into the low-to-moderate income level, and 9% of the households are living below the poverty limit. Additionally, the average household in Papakōlea has 4.61 people

compared to 2.95 people for the county as a whole. According to the Census, 37% of the homes have six or more people (American Community Survey - Hawaiian Home Lands, 2014).

The Native Hawaiian Health Fact Sheet of 2011 validates what Papakōlea observed. Native Hawaiian individuals contend with the stressors associated with the issues of their quest for self-determination and federal recognition to name a few. Indigenous place-based resilience requires understanding the traditions and sustained relationships with the land (Theron, Liebenberg, and Ungar 2014). Native Hawaiians are experiencing a public health crisis when analyzing chronic disease indicators, specifically cardiovascular disease, obesity, diabetes, asthma, and cancer. There are reasons why the Native Hawaiian population is not accessing proper/adequate health care. The reasons vary from financial, social, environmental, medical, and cultural.

Connection with the community and traditional Hawaiian values such as laulima (working together) focuses less on individualism which is a strength to the development of this community. Despite the relative success of Native Hawaiian organizations and groups to build cultural pride, positive identity, and holistic health in communities, the social marginalization of Native Hawaiians persists as reflected in social indicators spanning the breadth of the life cycle" (Ka'opua, Braun, Browne, Mokuau, & Park, 2011).

Hawaiian Homes Commission Act. The Hawaiian Homes Commission Act (HHCA) of 1921 was enacted "to enable native Hawaiians [3] return to their lands to fully support[i1] the self-determination of native Hawaiians and the preservation of the values, traditions, and culture of native Hawaiians is in the administration of this Act. This federal trust set aside approximately 200,000 acres in the State of Hawai'i to establish a permanent homeland for native Hawaiians, to enable a return to their lands to preserve the values, traditions, culture, and self-sufficiency of native Hawaiians (Umemoto, 2001).

Prince Jonah Kūhiō Kalaniana'ole, the first native Hawaiian to serve in the U.S.

Congress recognizing the terrible loss and struggles of his people convinced Congress to adopt a policy of ʻmina hoʻopulapula or "restoration [of Native Hawaiians] through the land." (DHHL, 2013). The HHCA reserves homestead land reserved for those who are of no less than 50 percent native Hawaiian ancestry…the vast majority of residents are of native Hawaiian or part-Hawaiian ancestry, except several families and the spouses of legal homesteaders. (Umemoto, 2001).

The HHCA was enacted on July 9, 1921, as a rehabilitation program and is still in effect today. At the federal level, the Department of Interior has oversight of the HHCA and Department of Hawaiian Home Lands (DHHL) at the State with a commission appointed by the Governor of Hawai'i. The mission of DHHL is "*to manage the Hawaiian Home Lands trust effectively and to develop and deliver land to native Hawaiians… [and] partner with others towards developing self-sufficient and healthy communities"* (DHHL Report, 2010).

DHHL provides "direct benefits to native Hawaiians in the form of 99-year residential, agricultural, or pastoral homestead leases for an aggregate term not to exceed 199 years at an annual rental of $1 (The State of Hawai'i, 2005). According to Hawaiʻi State Office of Hawaiian Affairs, 2015 the elderly (age 45 or older) was 25% or more of the population on ten of the 15 homesteads on O'ahu. The elderly was 50% of the Waimanalo Homestead. The increase in aging has an impact on all of our communities. As the only urban Hawaiian Homestead in the State, Papakōlea is densely populated with a significantly aging population, 26% of the total Papakōlea Homestead population.

Kula No Nā Poʻe Hawaiʻi. Kula No Nā Poʻe Hawaiʻi (Kula) is a 501(c) 3 Native Hawaiian community-based nonprofit organization formed by kūpuna of Papakōlea as a response to the disparaging level of education statistics and the increasing rate of illness amongst family and community members to create community-driven change. As a result of the work of these kūpuna the organization became a catalyst for change in the community in 1992. Kula enlists various partners to provide educational, health, and cultural programs and services for the residents of Papakōlea.

In 2017, Kula celebrated its 25th Anniversary. At that time reflection upon some of its most profound accomplishments in addressing the increasing rate of illness amongst family and community members was undertaken. Some of the accomplishments are the establishment of Nā Lomilomi o Papakōlea (NLOP) is the legacy of the late Somerset "Kalama" Makaneole and his vision of training a cadre of community members in his families' style of traditional lomi. In 1998, Kula recruited 12 passionate individuals to participate in Kalama's first class. His teachings focused on total body alignment with an emphasis on lomi, laʻau lapaʻau (herbal medicine), and spirituality. Since establishment, over 635 people have been served over 3,897 visits.

The PILI ʻOhana Project (POP) is a successful project (2009-2016) that originated with participation from Kula, four other community organizations, a team of academic researchers from JABSOM, and five additional community agencies which served as advisory roles. The goal of POP was to establish a community-academic partnership aimed at obesity-related disparities in Hawaiʻi and to implement a pilot intervention to address weight loss maintenance in Native Hawaiians and Pacific peoples.

Kula's founding members and their ancestors were incredibly passionate about supporting the educational skills of the children, and the healthcare needs of women and mothers in Papakōlea. In the 1920's, before the establishment of the Hawaiian homestead settlement, residents hosted public health nurses in their homes to provide well-baby clinics. These ardent women were determined to support the health and well-being of families. Thus, they broke-down barriers and established clinics in individual homes. Starting in 1992, Papakōlea has its first federally recognized community-based non-profit, Kula exists to honor Native Hawaiian history and culture by perpetuating and evolving traditional Hawaiian practices toward assuring community resilience, equity in health, and education for the residents of the region of Papakōlea Hawaiian Home Lands. It is with the understanding of this mission that the work in health and education

continues to flourish. In 1998, the community of Papakōlea participated in a vision project where they wrote: *our home is Papakōlea, a community where the spirit of lokahi and aloha inspires self-reliance and participation to share knowledge of our culture and respect of aloha. Residents assume responsibility to create a community with strong identity, spirit, and pride. Our participation nurtures our growth in education, economic well-being and improved health conditions for generations to come* (Hill, Queen Liliuokalani Children's Center, University of Hawai'i at Mānoa, & Papakōlea Community Association, 1998).

For most in Papakōlea, kūpuna are regarded as community treasures; their role is vital to the preservation of community history and culture. In 2008, Kula conducted a community survey of Papakōlea kūpuna, aged 55 and older. There 225 respondents, the top 5 chronic diseases were identified, 26.8% reported having diabetes which comes with many complications if it is not managed effectively. Interventions were implemented to address the other chronic diseases with programs such as PILI ʻOhana, Partners in Care, and KaHOLO for hypertension. When asked why there is so much work being done for the kūpuna population, the response is a concern for community. Kūpuna is ingrained in the culture of Papakōlea.

Since establishment, Kula has offered training and activities for the community on a macro level with a socio-educational focus on nutrition, exercise, healing, literacy, and family strengthening. Kula has a team of active Board members, dependable staffing, committed volunteers, and an assembly of partners that support the same vision of "moving toward greater health equity," and a history of successful collaborations. Members of this team are representative of and serve the people of Papakōlea skillfully. In fact, the commitment to community is so strong, that members not only volunteer in support of the community, but they have built their careers around service to Papakōlea in a grassroots venue or academically. This doctoral research study will assist the community of Papakōlea in the implementation of a culturally appropriate intervention that will help to

serve kūpuna with significant memory loss and their caregivers.

Kawaihonaakealoha (Respectfully Submitted with Love). The provision of the "Kawaihonaakealoha – A Project Respectfully Submitted with Love" since 2012 focuses on three main elements: 1) Coordinated direct assistance to kūpuna, 2) Culturally-sensitive community-led coordination of services, and 3) A service-learning program for nursing and social work practicum students. The current generation of leaders addressed the top five chronic diseases adopting a socio-cultural approach to developing programs and services while promoting the health and well-being of families carefully weaving fibers of health, education, culture, and community together into a final product for Papakōlea, the service-learning curriculum educates students on culturally appropriate health caregiving techniques to provide various health-related services to participating kūpuna in their homes.

This program began as a result of a CBPR project to address health disparities. Programs with the University of Hawai'i at John A. Burns School of Medicine (JABSOM), Department of Native Hawaiian Health (DNHH) has proven CBPR approaches to community-based healthcare to be successful, especially for the kūpuna population. It is imperative that families be given resources, (e.g., education and tools) to provide quality care for their treasured kūpuna in their homes AND their community. The community-university outreach team combined the ecological and system model to focus on the individual, his or her situation, and the effect of illness on the system and environment (Derauf, 2008).

Different services from personal care to home repair are provided to ensure the kūpuna are aging safely in place. The underlying premise is that better outcomes can be achieved in many indigenous community and communities of color with a more in-depth community-based cultural disease prevention model rather than a Western medical disease model. This systematic approach to disease prevention helps to understand culture as not static; generational differences between kūpuna, adults, and children are fluid with a direct

effect on care beginning with the kūpuna.

Traditional values when combined with community-based care for kūpuna and others cannot be replaced with institutional care, creating dissonance between traditional cultural values and modern realities. Innovation CBPR partnerships lie in the valuable insights into the effectiveness of "real-world" community-based collaborations. Under the guidance of community representatives, the "community-academic" care team develops chronic disease prevention education, which is reviewed and approved for cultural appropriateness by the community. Community leaders recognize the importance of nā kūpuna and continually seek guidance and advice from them. The community embraces the Olelo Noeau; *I paʻa i kona kūpuna ʻaʻola kākou e puka* (Olelo Noeau #1251). Had our ancestors died in bearing our grandparents, we would not have come forth. This is said to remind family members to respect the senior line because they came first (Pukui, 1983).

Health Equity. Health equity is broadly linked to social determinants such as socioeconomic status, the physical environment, discrimination, and legislative policies focusing on diseases and health care services (Mokuau et al., 2016). Native American, Alaska Native, and Native Hawaiians are indigenous populations with a shared history of forced colonization into the United States. Historical and cultural trauma has an impact on the pursuit of health equity. Health equity is elusive for Native Hawaiians, the indigenous people of Hawaiʻi, which is reflected in the excess burden of health and social disparities (Mokuau et al., 2016). Health equity emphasizes everyone 'attaining their full health potential,' and leaving no one disadvantaged because of his or her social position or other socially determined circumstances (Centers for Disease Control, 2013). Equity cannot be achieved if there is no constant monitoring and understanding of the social determinants of health of Native Hawaiians.

Health Disparity. Health disparity linked with a social or economic disadvantage impacting the health status. Health disparities negatively affect groups of people who have systematically experienced greater social or economic hardships resulting in

institutionalized obstacles that impact their health-seeking behaviors. These obstacles are historically linked to discrimination, social isolation, and civic exclusion based on race or ethnicity, religion, socioeconomic status, gender, mental health, sexual orientation, or geographic location. Other limiting factors include cognitive, sensory, or physical disability (Centers for Disease Control and Prevention, 2013).

Papakōlea Homestead Health Survey

In 2015, the Hawaiian Homestead Health Survey was mailed to approximately 392 homes with 125 adults (response rate 32.1%) over the age of 18 responding. The number of participants who indicated they had parents with ADRD or age-related dementia was 27 (25.9%), 15 with a maternal grandparent (14.4%) and 12 with a paternal grandparent (11.5%) (Antonio et al., 2016). The number of families impacted by ADRD or age-related dementia in the community appears to be relatively high for population size.

The 2015 Homestead Health Survey respondents had a median BMI of 31, which is categorized as being obese. Among survey respondents, 29% were overweight, and 51% were obese. Check these findings to information supported the State's BRFSS, concerning 76 of Hawaiian adults within the State of Hawai'i have excess weight, with 37% being overweight and 39% being obese. There were 40% Older Native Hawaiian adults have the highest prevalence and incidence of obesity, hypertension, and diabetes when compared with the dominant majority population in the United States (Browne et al., 2016). Hypertension, diabetes, and obesity are risk factors for dementia and are prevalent in Native Hawaiian kūpuna of Papakōlea. The top five chronic diseases identified in the survey in 2008 by kūpuna aged 55 and older were hypertension, diabetes, asthma, arthritis, and cataracts.

The 2015 Papakōlea Homestead Health Survey reports there was a history of diabetes in 23% (N=29) of survey respondents. The Papakōlea rate is above the numbers found for Native Hawaiians statewide. Also, the rates for Papakōlea was

exceeded by all Hawai`i residents and the U.S. overall, as ten residents with ADRD reported a history of diabetes (Antonio et al., 2016). The stigma of ADRD has been known as a barrier to tending to and seeking services for care recipients. ADRD stigma involves three domains (public avoidance, pity, shame) and their roles within the intention, attitude, subjective norm, and perceived activity control Papakōlea numbers exceed the national and state average. Of the 125 responding to the survey, most were female (72%) and ranged in ages from 24 to 95 years. The majority (55%) of our respondents were between the ages of 50 and a variety (99%) chose Native Hawaiian as either their ethnic identity or one among their ethnic identities (Antonio, et al., 2016).

These statistics coupled with ADRD being the sixth-leading cause of death in the U.S. demands that society understand the urgency in addressing the impact of ADRD in the Native Hawaiian community (Kenneth Kochanek, Murphy, Xu, & Tejada-Vera, 2016). Data on Native Hawaiian kūpuna population remains sparse, and attention to the health needs and care preferences specific to nā kūpuna (elders) and family caregivers, while growing, remains at a nascent stage (Browne et al., 2014).

Community care is necessary to help caregivers of the sandwich generation, the middle-aged generation who have elderly parents and dependent children or grandchildren as the aging population increases. Studies are required to understand the stress experienced by caregivers and how to adequately meet the needs of the kūpuna presenting symptoms of memory loss (Pieret, 2006). Pearlin suggests the essential element of the sociological study of stress is the presence of similar types and levels of stress among people who are exposed to similar social and economic conditions, who are incumbents in similar roles, and who come from similar situational contexts 1989). These elements exist among the Papakōlea caregivers. Therefore, there is an inquiry about caregiver stress included in this study.

In a dementia friendly community, people living with dementia have autonomy, high

quality of life, and are engaged with the community. The right community services and supports make this possible by taking a "whole person" or person-centered approach that helps people with dementia and their care partners live meaningful lives and reach their full potential (Dementia Friendly America, 2015). Addressing the mental abilities of an aging population requires an understanding of what is normal aging and how to inquire about conditions such as ADRD to healthcare providers.

Social Determinants of Health. Discussion of health improvement is multi-faceted. Social circumstances and environmental factors put Native Hawaiians at a distinct disadvantage in health and disease, creating disparate health conditions (Browne et al., 2014). Addressing social determinants of health is a primary approach to achieving health equity. Social determinants of health are economic and social conditions that influence the health of individuals and communities. Social determinants of health affect factors that are related to health outcomes (Centers for Disease Control and Prevention, 2014).

Any effort to address Native Hawaiian health disparities must be grounded in an understanding of the historical past and ongoing impact of colonization by the United States. Hawaiians have suffered collective depression as the result of "historical trauma," political overthrow and marginalization, change in subsistence practices with economic deprivation, population decline from introduced diseases, land alienation and urban relocation, religious suppression and cultural repression, with resulting loss of self-concept. This trauma is experienced on an individual and collective level and transmitted from one generation to the next (Brave Heart, 2011).

Life expectancy for Native Hawaiians is 6.2 years lower than the life expectancy for any other group in the State of Hawai'i, even though Native Hawaiian life expectancy has increased by 11.8 years since 1950. Hawai'i state data indicate that Native Hawaiians have higher rates of death in comparison to all other ethnicities in Hawai'i. Similar to Blacks across the nation, Hawaiians are dying at younger ages, with dramatic differences

starting in the mid-life age range (Look**,** Trask-Batti, Agres, Mau, & Kaholokula, 2013).

Community-Based Services. This study is the first of its kind to gather the concerns of Native Hawaiian Homestead caregivers providing care to a family member with memory loss such as dementia and other chronic diseases. Traditional Native Hawaiian culture honors and values kūpuna and family caregiving, and yet the demands of providing dementia care to a family member is daunting. As community-based services are implemented there is a need to ensure programs are prepared to address the desire of kūpuna wanting to age safely in place.

Culturally safe research reflects "culture" as multi-dimensional, that community empowerment is intricately linked to cultural safety which is relationally-based, and that safety is holistic with systemic and community factors influencing personal perceptions (Tamang, 2014). It is crucial one understands that culturally sensitive research should incorporate attention to the ethical values of Hawaiian culture, cultural values of Papakōlea, and other Homestead communities that promote cultural safety.

Culturally sensitive research approaches must be viewed as legitimate, appropriate, and critical to understanding the experiences of "others." The recognition of culturally sensitive research approaches has been minimized given the tendency of some researchers to study indigenous and people of color from deficit perspectives. It can be acknowledged that all research can be considered culturally based and that culturally sensitive research approaches including emerging paradigms in qualitative research have presented opportunities for collaboration, insider perspectives, reciprocity, and voice can be applied in a broad sense to people of color. Cultural resistance includes theoretical dominance, culturally sensitive data interpretations, and culturally informed theory (Tillman, 2002).

Native Hawaiians must have cultural connections with practical applications when involved with research to address different conditions. This necessity has intensified through cultural revitalization causing cultural relevance to become increasingly appealing

to opio (youth), makua (adults), and kūpuna. In the late 1960's and 1970's, the greater Hawaiian community experienced a cultural renaissance, a broad cultural movement in Hawai'i under a 'local' consciousness that has a strong indigenous base requiring strong grassroots activism (Wilson, 1998). The Renaissance produced growing interest in Hawaiian language, music, traditional navigation and voyaging, and hula, and sparked new pride amongst Hawaiians (Burnette, Morrow-Howell, & Chen, 2003).

Cultural Based Programs. Papakōlea has participated in some successful culturally based and culturally tailored interventions during the partnership with the University of Hawai'i at Mānoa, John A. Burns School of Medicine (JABSOM) Department of Native Hawaiian Health (DNHH). Historically, residents of Papakōlea have been engaged to address the concerns of the community. Cultural-based programming supports a healthy community is one connected to itself, to others, to place, and to the past and present fostering broader wealth and well-being. Cultural awareness spawned political activism seeking greater autonomy and sovereignty, protection of traditional native gathering rights, and more. However, cultural-based programming had not become institutionalized until much later (HawaiiHistory.org, 2017).

In fact, the community's proclivity for cultural-based programming has helped to attract families to holistic health practices that innovatively integrate health, education, culture, and community. For example, the Board and Stone (B&S) Program, is one of Papakōlea's most recent successful culture-based programs. The B&S Program is a cultural curricula program that was coordinated for Papakōlea by Kula.

Native Hawaiians have a genealogical relationship in creation mythology. Using the cultural curricula to facilitate lessons participants were taught to make traditional implements for the preparation of poi. Poi is the nutrient-dense indigenous weaning food for infants and preferred dietary staple across the lifespan. Participants learned cultural protocols, key Hawaiian words, use of traditional tools, and traditional

teaching methods (Titcomb, Dillard, Morris, Brinker, & Kawa'a, n.d.).

> Eighty-five families participated in the series in the last 12 months, making it one of the most popular programs to date. The approach in this program was to create a safe environment where participants develop confidence and competence to become family and community agents of change. The program did not aim to displace unhealthy foods nor to restore healthy dietary practices. Participants also took part in indigenous storytelling methodology to describe their experiences. Qualitative analysis revealed three popular themes: cultural connection, family strengthening, and community engagement (Titcomb, et al. 2016).

The PILI 'Ohana Project (POP) is another successful project (2009-2016) that originated with participation from Kula, four other community organizations, a team of academic researchers from JABSOM, and five additional community agencies which served in an advisory role. The goal of POP was to establish a community-academic partnership aimed at obesity-related disparities in Hawai'i by implementing a cultural adaptation of the Diabetes Prevention Program to pilot an intervention to address weight loss maintenance in Native Hawaiians and Pacific peoples. These programs highlight a need and acceptance of culturally based solutions as communities seek health equity.

Community Engagement. A majority of older Americans prefer to age in place and stay in their own home or at least continue to live in the community as long as possible (Burr, Mutchler, & Warren, 2005) One strategy is to expand home- and community-based services by improving local service infrastructures and community partnerships. Because of personal relationships family caregivers are relatives, partners, friends, or neighbors who provide help that may include arranging and attending medical appointments.

Caregivers ensure that older adults' needs for food and shelter are met while participating in routine and high-stakes treatment decisions, coordination of care and

provision of services (Wolff, Feder, & Schulz, 2016). The support provided is not for financial compensation). The provision of a variety of flexible services under innovative delivery systems will help meet the changing (Kelly, Reinhard, & Brooks-Danso, 2008; Wolff, Feder, & Schulz, 2016). Without caregivers, people with dementia would have a more inferior quality of life and would need institutional care more quickly, and national economies would be swept away by the advancing demographic tidal wave (Brodaty & Donkin, 2009).

Family caregivers of individuals with ADRD, often called the invisible second patients are critical to the quality of life of the care recipients. The literature does indicate that stress has an impact on caregiving with many caregivers winding up becoming patients themselves. Missing from the literature was the enjoyment level of caregivers. While many caregivers report that they derive significant emotional and spiritual rewards from their caregiving role, many also experience physical and emotional problems directly related to the stress and demands of daily care (Roberts & Struckmeyer, 2018). Despite the high prevalence of dementia, negative community attitudes and stigma towards dementia are still common (McCloskey et al., 2017).

Caregivers report adverse psychological, physical, social and economic impacts related to caregiver burden. Factors contributing to caregiver burden include older age, income, family and social support, and coping strategies (Bolda, Saucier, Maddox, Wetle, & Lowe, 2006). The literature implies that most caregivers are female and in a homestead community where families have lived for generations, the findings for Papakōlea supports this concept with the majority of the caregivers being female. It also states, that many families still do not plan for long-term care, it seems to be more of an economic barrier to pay out the cost for this type of insurance. Research conducted by Hā Kūpuna, the National Resource Center for Native Hawaiian Elders at the University of Hawai'i at Mānoa reports two themes emerging from their studies on Nā kūpuna and ʻohana caregivers. First, there is a myriad of challenges and cost associated with growing old and the challenges of

caregiving.

There is a dual impact of core cultural values and social stressors (e.g., discrimination as perceived in disrespectful care and services) that influence elder and caregiver needs and preferences (Browne et al., 2014). Neither kūpuna nor ʻohana caregivers are prepared for the myriad of challenges associated with growing old. Many have not given thought or time to prepare for how life will differ when faced with the change in socio-economic status that for many come with retirement coupled with a possible declining of mental and physical health that precedes an imminent need of caregiving.

Families of persons with dementia face unique challenges that a lot of different caregivers do not. The core options of features embody a cluster of neuropsychiatric symptoms comparable to depression, apathy, sleep disorders, agitation, and psychosis. People with dementia could have multiple psychological, biological, and social unmet needs, losing grasp of their understanding of their circumstances and relying heavily on their family for all aspects of their physical and emotional support, including as activities of daily living. This level of care will be intense and physically exhausting, and challenges are exacerbated if caregivers are in poor health themselves.

The literature review guides the development of the research questions working in conjunction with Papakōlea community leaders invoking the CBPR approach which compelled their participation in development and concurrence on the decision-making on the implementation of this research study; the process of getting survey questionnaires; eliciting sociodemographic characteristics, and knowledge-attitudes-behaviors on caregiving for residents. Understanding the complex dynamics of ADRD, caregiving, and community at the nexus of Native Hawaiian culture is proving to add significant value to this study.

CHAPTER 2. METHODS

This research is grounded in Community-Based Participatory Research (CBPR) principles and utilizes a mixed methods strategy to assess the needs and concerns of caregivers.

Community-Based Participatory Research (CBPR). The Papakōlea community has embraced the use of CBPR for the valuable insights into the effectiveness of "real-world" community-based partnerships that exemplifies the innovation of CBPR. In CBPR the intent is for this research to benefit the community which is a group sharing a common physical environment, resources, and services, as well as risks and threats and as a collective body that has geographic boundaries, internal and external feedbacks, and "shared fate." (Longstaff, Armstrong, Perrin, Parker, & Hidek, 2010). In Hawai'i, CBPR has been successful in building community capacity because of the support provided by the researchers of the University of Hawai'i and other committed researchers.

In the past, there have been challenges to get communities to participate in research in a meaningful way. The community of Papakōlea had closed its doors to researchers in the 1970's. There was a history of researchers in this community, conducting their research without even returning to discuss their findings. This research left the community unaware of how they had been portrayed and unable to access or use the data that had been collected from their residents who were research participants. The access by researchers in Papakōlea has only regained acceptance over the last two decades. A CBPR approach was utilized in Papakōlea because it is what the community has come to understand and expect to build capacity during research.

As community-based participatory research achieves larger acceptance in the research community, it becomes essential within the field to interact within the science of discovery and to be told how CBPR pathways work to push new capacities, system changes, and health outcomes, each to come up with stability for the field and to reinforce the collective ability to possess an impact on health status and health equity. (Minkler &

Wallerstein, 2008).

A multi-layered model of interconnected domains, the socio-ecological perspective also incorporates a variety of concepts derived from systems theory such as interdependence, homeostasis, and feedback, to better understand the interaction between people and their environment (Stokols, 1996). Guiding the ethical considerations for this research are "three fundamental ethical principles that are relevant to all research involving human subjects: Respect for Persons, Beneficence, and Justice. Although other important principles apply to research, these three provide a comprehensive framework for ethical decision-making in research." (National Institutes of Health, 2004)

The ecological and system theory models that focus on the individual, his or her situation, and the effect of other influences on the person in the environment. This socio-ecological approach recognizes that culture is not static; and that a myriad of factors has a direct effect on overall well-being. In general, the social-ecological approach takes a broad stance that views human behavior in a more significant social, institutional, and environmental context and encourages a break from traditional disciplinary boundaries, and is sometimes referred to as a transdisciplinary or interdisciplinary in approach (Hiatt & Breen, 2008; Stokols, 1996).

Papakōlea was a community partner in a "best practice" model of CBPR in Native Hawaiian and Pacific Islander communities that emerged from the community-academic partnership of the PILI ʻʻOhana Project (POP) from the University of Hawai'i at Mānoa, JABSOM, Department of Native Hawaiian Health. As a result, the partners built the capacity, social capital, and critical consciousness necessary to adequately address their community-driven health concerns (Kaholokula, 2013). This project included this community researcher, others from Kula, and four other community organizations for obesity-related disparities and implementation of a pilot intervention to address weight loss maintenance in Native Hawaiians and Pacific individuals (Kaholokula, 2007).

An important area of emphasis in CBPR over the past several decades has been the building of social capital through the research process. There continue to be questions about how the characteristics of CBPR are actualized in a manner that is of benefit to the community who are perceived to be equal members of the research team. Brokering an effective relationship remains challenging, and the mistrust of research in indigenous and minority communities exists because of past research atrocities. Therefore, as these relationships are built there is a continuous need to determine that community-academic partnerships remain equitable.

Various members of the Papakōlea community have been engaged through the course of this research process assisting with the development of the research questions, finalization of the research questions, development of the survey questionnaires, testing the surveys, mailing of the surveys and gift cards, and facilitating focus groups. The collaboration with the community will continue through to the final report to the community. Kula research collaborations have utilized CBPR for over a decade.

The community has been exposed to different research methods and approaches such as CBPR and ethnography while addressing health disparities among Native Hawaiians and Pacific Islanders in partnership with the University of Hawai'i, John A. Burns School of Medicine (JABSOM) Department of Native Hawaiian Health (DNHH) for over a decade (Dillard, Carpenter, Mau, & Kekauoha, 2004). CBPR recognizes community as a single unit, which means that the collective and individual identity forms the basis of this research approach. It considers the community as all socially constructed interactions significant in many forms such as friends, family, and geographical neighborhood. It also takes into consideration the social norms, shared values, emotional connections and common interests to meet a shared need (Wing, 2002).

The CBPR Model for this research project uses contexts to validate health issue importance, which includes the severity perceived by partners (caregivers) and capacity and readiness of community (community leaders, Kula) and academic (researcher).

Additionally, under Intervention and Research, Fit will examine at cultural knowledge norms and practices to inform importance of health issue (see figure 2). CBPR begins with a research topic of relevance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities (University of Berkeley School of Public Health, 2012).

The work in Papakōlea in the health arena is guided by a practice design that allows for a whole-person approach. This method is mindful of culture and social needs of individuals using a community-based paradigm (CBP). This CBP identifies and builds on the reciprocal relationships of social, emotional, and physical forces striving for balance.

Indigeneity in the research approach brings a different type of understanding of the cultural context in which the research participants exist to inform research outcomes.

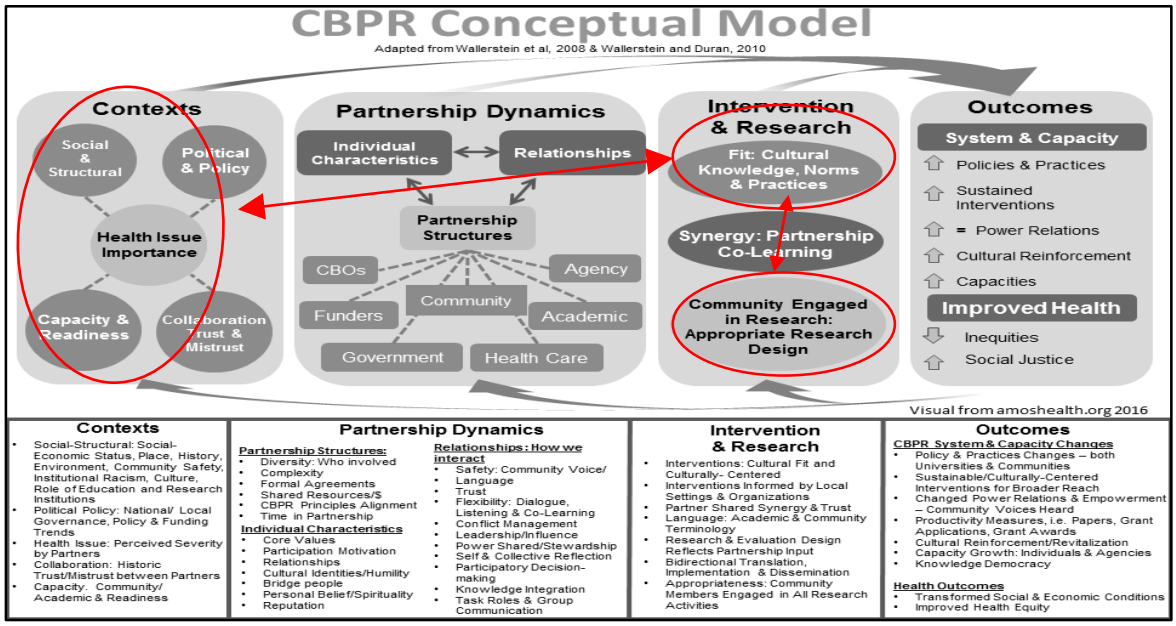

Figure 2. CBPR Conceptual Model (Wallenstein and Duran, 2010)

Community leaders have approved this study. Thus, CBPR was used for all methods of data collection, analyses, and dissemination, when possible (Ka'opua, et al., 2017). As in past research, any disagreement on tools or processes is subject to review by the Community Advisory Board to determine what is in the best interest of the community.

If an agreement cannot be reached, the research will be postponed until community leadership determines that there will be no harm to the community or the integrity of the study. The CBPR approach has been utilized in research in Papakōlea for over a decade and been of great benefit to the community development.

In conducting this research, there is an expectancy that there will be a positive correlation between knowledge and resources available and caregivers' perception of need. The use of CBPR will support the premise that as communities play a more active role in research, they will gain essential skills in identifying problems/issues and addressing those using appropriate solutions, specific to their communities. In doing so, they will become more empowered.

Many CBPR projects have been conducted, and the process surrounding the research principles of partnership and community capacity building is under study from what communities' lack. Determining whether a partnership meets the needs of the community partners is one area that needs additional review. One common thread is that most programs do not allow equal access to financial decision-making, therefore leaving communities unequal partners in a process that was developed to pursue equal ownership of the research process for the betterment of community health disparities.

As noted above, one problem area is the fact that many communities are skeptical of researcher motives. Not engaging in research to understand disparities can affect their overall state of well-being for the neediest communities. Some communities can cross these hurdles of mistrust through CBPR, while others find themselves less equipped to participate in this process. Understanding the social capital increase as part of the process could help to persuade groups to participate. The second problem area involves better understanding why some people turn to learn to meet personal needs, while others do not.

When communities participate in the decision making power, support, and information sharing strong partnerships are formed. The CBPR model incorporates a model

that requires a long-term commitment of the partners involved. Given the emphasis on an ecological approach to health, the model also develops skills, infrastructure, and trust that allow the creation of comprehensive research interventions, capacity, and readiness.

It was imperative that the CBPR approach was utilized for this study to be conducted in the community of Papakōlea. When focusing on the CBPR conceptual model it helps to align the research study contextually with a health issue of importance, social and existing and future social and structural framework, community engaged in the research; advising on the appropriate research design and engaged in the research process. Additionally, the results of the survey will help to determine the capacity and readiness of the community to implement a culturally appropriate intervention, if warranted.

CBPR as a conceptual model with the socioecological framework as the theoretical framework helps to align the complexities of the caregiving realities.

Theoretical Framework

Socio-Ecological Theory (SET). The socio-ecological theory is reflective of environmental systems. The smaller system includes family, peers, friends, and schools all of which impact one's most crucial developmental years. Studies indicate constant positive interaction in human development throughout the lifespan to include others is essential to healthy aging. Human development is affected by the unpredictability and instability of family life and may impact one throughout their life cycle. If relationships are fractured, one seeks attention in appropriate places. The latter system was added to reflect impacting situations that occur such as death having a developmental impact. The five systems are used interchangeably throughout the lifespan.

Reminiscent of the socio-ecological theory, this kūpuna project recognizes the kūpuna and family at the center of the engagement cycle and surrounding partners as equal parts of an expansive care team that assists with providing support not only to the kūpuna but recognizes the importance of the ʻohana and the training of community in the pursuit of health equity. When working with the community, one must understand that for

Native Hawaiians, affiliation or reliance on informal networks of family, friends, and peers is an important coping mechanism when health problems arise (Aluli, 1990). Kūpuna and caregiver needs can be met when they can access needed resources without time gaps.

Unfortunately, typical health programs focus on treatment of the individual, without consideration of the family or community involvement. This is in direct conflict with Native Hawaiian culture, as the individual seeks to restore health navigated through systems by a family who understands their need for both traditional and western healing methods (Derauf, 2008). This treatment of the individual only needs to be taken into consideration when assessing community capacity and readiness when culturally tailoring interventions to build support services and resources for caregivers of Native Hawaiian kūpuna with significant memory loss due to aging and ADRD.

Understanding systems and developmental stages of caregivers is useful when transcribing focus groups. The theoretical framework for this research is the Social-Ecological Theory (SET) (Stokols, 1996) and the PEN-3 Model. The socio-ecological theory combines the ecological and system theory models to assist in focusing on the individual, his or her situation, and the effect of other influences on the person-in-environment (University of Hawai'i Integrated Pediatric Residency Program, 2008).

This theory allows one to understand that whether it provides empirical support or empirically to contradict them, the aim is to encompass all the level of analysis that is to be understood by the individual psychology. Levels of environment and time influence individuals. This socio-ecological theory supports that a myriad of factors has a direct effect on overall well-being. In general, the socio-ecological approach takes a broad stance that views human behavior in a larger social, institutional, and environmental context and encourages a break from traditional disciplinary boundaries. (Hiatt & Breen, 2008; Stokols, 1996).

As a multi-layered model of interconnected domains, the socio-ecological perspective also incorporates a variety of concepts derived from systems theory such as

interdependence, homeostasis, and feedback, to better understand the interaction between people and their environment. The ecosystemic view of individuals is embedded in a web of complex, interacting relationships. (Stokols, 1996). Briefly, Systems Theory describes how a set of interrelated elements is organized as a functional whole and the manner in which they adapt to change (Zastrow & Kirst-Ashman, 2010).

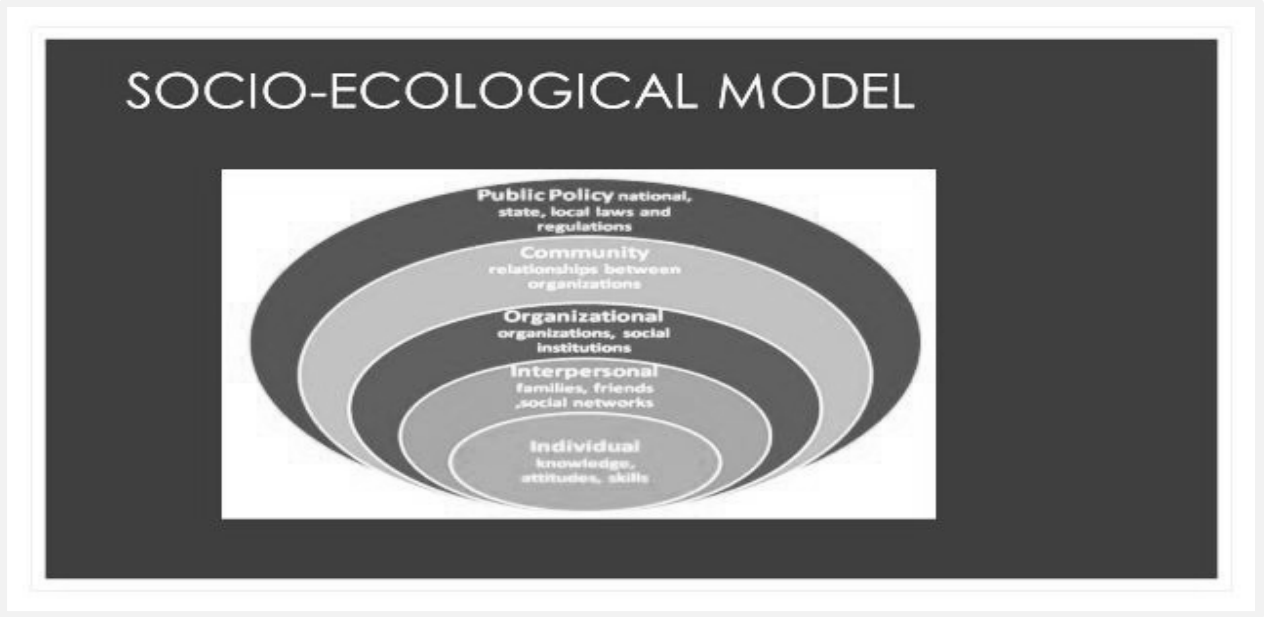

Figure 3. Socio-ecological Model Source: Bronfenbrenner

The conditions associated with caregiving allows an individual, the family unit, community, and broader environment to rely upon the interconnection of systems, and factors from each realm to contribute to processes that can counter stress and adversity. The impact of the disease may require one to call upon groups of people located in a web of meaningful relationships. SET will contribute to understanding the various roles of caregiving and the impact across systems. The theory is used to attempt to place a plausible explanation of cause and effect relationships.

SET is a powerful tool to understand the environmental influences on the caregiver and the kūpuna life. There is need to understand how family, community and the societal influences will support the caregiver's life and how other parts of their life outside of

caregiving either enable or disable the ability to provide adequate care or connect to resources outside of the home to avoid caregiver burnout. Similarly, it helps one understand how broad aspects such as various ecological systems impact the care of both the caregiver and the kūpuna.

The use of this social-ecological theoretical framework has garnered success in other programs at the Papakōlea Community Center. Crucial assessment occurs at the interface; or transaction between the individual; their systems that are interdependent, moreover, the environment. Change and adaptation to illness affect all within the system: the individual, their family, the community and surrounding environment (University of Hawai'i Integrated Pediatric Residency Program, 2008).

This theory defines a complex layer of human development which is impacted by existing in the environment and systems. This theory was renamed from ecological to system theory to emphasize that a child's biology is a primary environment fueling his or her development (Hess & Schultz, 2008).

> As a multi-layered model of interconnected domains, the socio-ecological perspective also incorporates a variety of concepts derived from systems theory such as interdependence, homeostasis, and feedback, to better understand the interaction between people and their environment (Stokols, 1996).

Each system nested within the other systems has an impact on all developmental stages. Human development is an ongoing process that crosses the lifespan. The synergy of these systems flows bidirectional. The changes or conflict in any layer will be ripple throughout the layers.

The socio-ecological model was used to guide the adaption of the diabetes prevention program materials and the development of the PILI Lifestyle Program curriculum and its family and community focused strategies. It was also used by each of the community partners to build capacity within their respective communities to address the issue of overweight and obesity (Kaholokula et al., 2014). Therefore, there is cognizance of this

model for guidance while culturally tailoring an intervention for use in Papakōlea. The complexities of addressing the impact of memory loss require we look at systems at various levels. As the memory loss occurs in stages and many of our kūpuna have indicated that they may receive from friends and families, the social-ecological model will be utilized to frame responses by various groups.

The individual, family unit, community, and larger environment are interconnected, and factors from each realm contribute to processes that can counter stress and adversity. This perspective is shifting resilience research towards an emphasis on collective processes, strengths, and assets (Richardson, 2002). It was primarily conceptualized that validating this theory utilizes a methodology to characterize and quantify specific sources of impact observed measurement can be made. This research will benefit from participation in the DFA Initiative that is catalyzing a movement to more effectively support and serve those across America who are living with dementia and their family and friend care partners (Dementia Friendly America, 2015).

The PEN-3 model is used to place a cultural context to the qualitative data and the theoretical framework, as culture is an area that was missing from this socio-ecological and systems theory from Bronfenbrenner and others. The framework represents theoretical and methodological possibilities for more culturally informed research, theory, and practice (Archibald, 2011). While gathering data to meet the needs of kūpuna information obtained efficiently can guide program development and social policy advocacy.

PEN-3 Model (PEN-3). The model is used to attempt to place a plausible explanation of cause and effect relationships. The PEN-3 Model uses the following dimensions: (a) Cultural Identity (person, extended family, neighborhood); (b) Relationships and Expectations (perception, enablers, nurturers); and (c) Cultural Empowerment (positive, existential, negative). The dimensions are used to "contextualize" findings to align with the theoretical paradigm (Melancon, Oomen-Early, & Del Rincon, 2009). The PEN-3 can be used as an analysis tool, to sift through text and data to

separate, define and delineate emerging themes.

PEN-3 MODEL

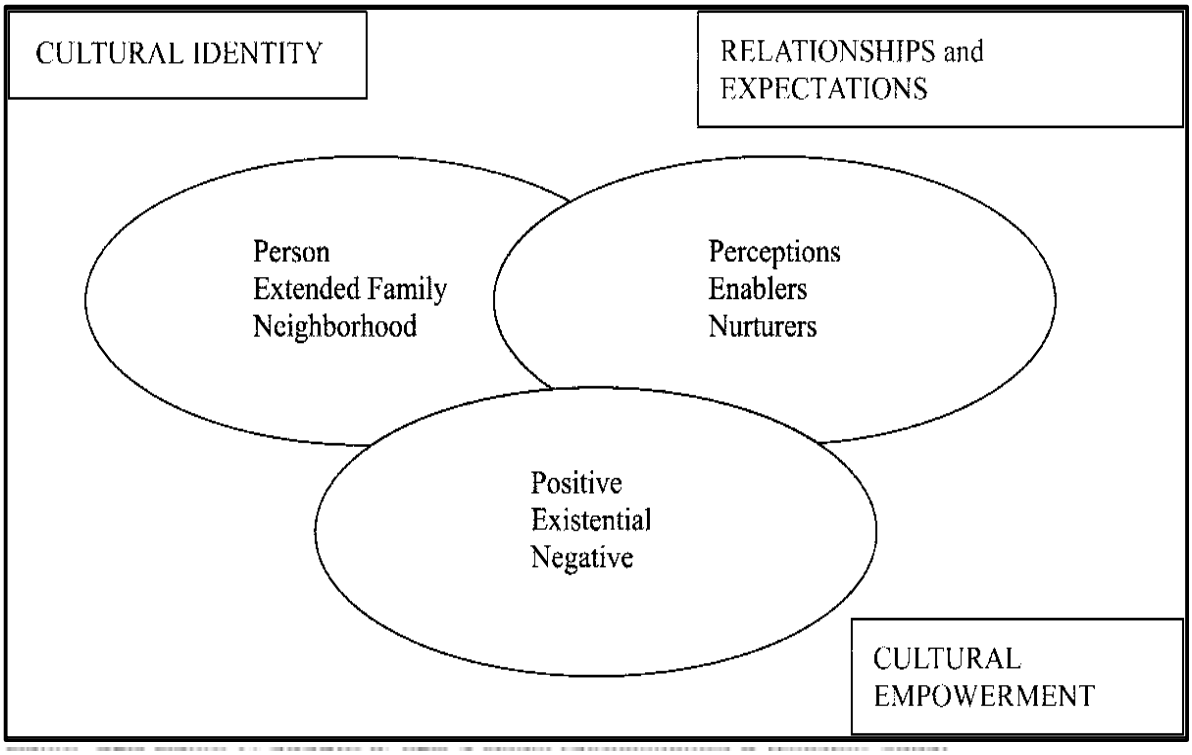

Figure 4. The PEN – 3 Model.
Source: Airhihenbuwa & Webster (2004)

The PEN-3 is useful when exploring not only how cultural context shapes health beliefs and practices, but also how family systems play a critical role in enabling or nurturing positive health behaviors and health outcomes (Iwelunmor, Newsome, & Airhihenbuwa, 2014). The PEN-3 model is a qualitative analysis of the first dimension of ***Cultural Identity*** that helps to define the target audience (person, extended family, and neighborhood). ***Relationships and Expectations***. This dimension determines the factors (perceptions, enablers, and nurturers) influencing the actions of the target audience (Melancon, Oomen-Early, & del Rincon, 2009). Additionally, the PEN-3 model will be used to assess knowledge, attitudes, and beliefs regarding caregiving. (Iwelunmor, Newsome, & Airhihenbuwa, 2014).

Now, referenced more as social capital (partnerships/collaborations), this critical

element remains constant in building individual, organizational and community capacity, to address the health disparities of Papakōlea. ***Cultural Empowerment*** *of the Pen-3 Model*. This component is vital in the development of culturally sensitive interventions and instruments to assess the target health behavior of ethnic minority cultures (Melancon, Oomen-Early, & Del Rincon, 2009). Papakōlea community leaders address health equity with research that honors our cultural values and traditions while embracing change that community forward, always respecting the ways of their ancestors and kūpuna.

The following table of focus group data uses both the socio-ecological theory and PEN-3 Model as we analyze information to address possible interventions.

Table - PEN-3 MODEL/SOCIO-ECOLOGICAL MODEL – FOCUS GROUP RESPONSE

Socio-Ecological Theory	**PEN-3 Model Cultural Identity**	**PEN-3 Model Relationships & Expectations**	**PEN-3 Model Cultural Empowerment**	**Focus Group Response**
Individual, Interpersonal	Neighborhood	Perceptions Enables	Positive	The family has to work together – can be confusing with many different opinions
Individual, Interpersonal, Organizationss, Community, Public Policy	Person	Nurturers	Positive	Getting access to services where to start.
Individual, Interpersonal, Organizationss, Community, Public Policy	Neighborhood	Enablers	Negative	Need to plan and start conversations early on financial planning, - Medicaid/Medicare
Individual, Interpersonal, Organizations, Community	Extended Family	Perceptions	Negative	Women tend to be natural caregivers
Individual, Interpersonal, Organizationss	Neighborhood	Enablers	Negative	Some men have trouble communicating
Individual, Interpersonal	Person	Perceptions	Existential	Men are in denial
Individual, Interpersonal, Organizations, Community,	Extended Family	Nurturers	Negative	Some kūpuna are hard to help, become combative, angry, cussing
Individual Organizations	Neighborhood	Nurturers	Positive	Hard for men to provide feminine care both for caregiver and kūpuna, especially when providing for mom
Individual, Interpersonal, Organizationss, Community, Public Policy	Extended Family	Perceptions	Negative	Not prepared for the role as a caregiver
Individual, Interpersonal	Neighborhood	Perceptions	Negative	Hard to face the decline in kūpuna health when they were very active, still need to leave kūpuna with dignity

HILINA'I. is a model of community-based safety for indigenous and communities of color to ensure building trust and cultural safety. It is important that researchers be prepared for meeting communities exploring a research platform to build their capacity that community can be engaged on their terms. The research process may begin with some assurance. General guidelines for culturally safe health practice are premised on the recognition of group strengths in surviving cultural trauma and coping with ongoing marginalization. Providers practicing cultural safety strive to make health services more welcoming by demonstrating respect for all ways of knowing, openness to reciprocal learning, and importantly, monitoring their negative biases.

	"HILINA'I"
	Building Trust and Cultural Safety in Research Praxis
H	Honor a community's history of strength and resilience, vision for health-wellness, lifeways, and research needs and priorities.
I	Introspect on personal, professional, and organizational biases that may influence negative attributions of poor health outcomes in a community and among its members.
L	Learn community ways of knowing and transmitting what is known. Be open to learning from kia'i, kūpuna, traditional practitioners, and other community members.
I	Involve self in community activities, get to know community as more than a study site and to know residents as more than (potential) study participants. This may set the foundation for holistic and enduring relations with community and its members.
N	Nurture meaningful community participation in the research endeavor across the trajectory of a project—from needs assessment to intervention development, evaluation, and dissemination of findings.
A	Act to enhance research capacity of persons-in-community and of community as dynamic organization. Partner/mentor on specific research activities when possible, and know when to "release" resesarch leadership to community members.
'I	Insurrect relationships of unequal power and control through culturally-grounded relationships and dialogic processes.

Figure 5. HILINA'I Cultural Safety Source: (Ka'opua, Tamang, Dillard, Kekauoha, 2017)

Cultural safety was paramount to ensure was observed during the project in Papakōlea. During the project, the researcher determined how each component would be expressed during interaction with community members. It is crucial that community feel that their ideas, concerns, culture, and community are being honored and respected during the research process. The following table expresses how HILINA'I cultural safety model was used during this research study.

To ensure cultural safety, the community of Papakōlea was honored for its history of strength and resilience, vision for health-wellness, lifeways, and research needs and priorities during the course of the research study. All available information was documented and shared through the many drafts of the study with the community. Introspect on biases that may influence negative attributions of poor health outcomes in Papakōlea and among its members was constantly considered and addressed. Learning earned from community members that best way to conduct both methods, qualitative and quantitative research included learning from kūpuna, traditional practitioners, and other community members. One of the key lessons involves understanding self and role in community activities to get to know more community members. Built upon existing relationships with the Kula staff and residents to ask for help.

It is important to nurture meaningful community participation in the research endeavor across the trajectory of a project—from needs assessment to intervention development, evaluation, and dissemination of findings. One should act to enhance the research capacity of persons-in-community. Moreover, the community as a dynamic organization. The research was released to the community for the outreach, focus group and data entry. Understanding the role of community is very important when researching the community. The community took the lead on outreaching for the return of surveys. Insurrect relationships of unequal power by establishing understanding relationships which were formed during this process; there was agreement on most cultural expression between the researcher and community members.

Strength/Limitations. A strength of this research study includes its design and implementation. Individuals directly involved and thoroughly familiar with Papakōlea will conduct the study. The mixed-methods design of the study allows for both qualitative and

quantitative data collection, enabling study participants to provide context, explanations, perspectives, and opinions of their experiences. There are limitations to the study. First, the study will be limited regarding its generalizability to other populations not defined by geographic boundaries because it is premised on a strengths-based, ecological perspective. The homestead communities are a very heterogeneous population. While the proposed study should be quite diverse, the fact remains that certain subpopulations in Hawai'i will not be included.

Findings from this study are community-specific and cannot be generalized to all Native Hawaiians and Native Hawaiian communities. However, findings from this research performed in one urban homestead community may provide critical considerations for others interested in developing policy and research for/with elders and family caregivers in the context of ADRD. There are differences between homestead communities across the state in the expression of Hawaiian values and practices and degrees of community resilience.

Therefore, this study may not be representative of all homesteads statewide. Additionally, the results may not be to other Hawaiian Homestead communities. The methodology will capture information that is acceptable and relevant. Self-identification of ancestry introduces systemic error. Attitudes towards Native Hawaiian identification have changed over time.

The limitations of the study include its small sample size. We are not able to obtain a baseline measurement to gauge the level of capacity initially experienced by caregivers at the onset of the disease due to its retrospective nature. In as such, the study may be subject to recall bias. The credibility of the research will take into consideration the relationship that already exists with many of the community residents and knowledge of community history and organizations. The rapport established will reinforce that information is being used to inform the process. Despite these many limitations, there is interest in and value to a descriptive study of caregivers of Native Hawaiian impacted by

abnormal age-related memory loss and ADRD.

This mixed methods study was conducted to provide an optimal understanding of the complex dynamics of ADRD, caregiving, and the community at the nexus of Native Hawaiian culture in Papakōlea Hawaiian Homestead. This research proposal was approved by the Institutional Review Board of the University of Hawai`i Committee on Human Studies to minimize risk, ensure protection, and guarantee voluntary participation. Study protocol approved on March 7, 2018 approval number 2018-00038.

Several researchers have developed typologies for classifying MMR approaches (Creswell & Plano Clark, 2007; Onwuegbuzie & Combs, 2010; Tashakkori & Teddlie, 2010). In earlier work, Creswell and colleagues (2003) classified MMR designs into two major categories—sequential and concurrent. This study used a sequential exploratory design (QUANT-QUAL) with each phase addressing complementary aims within this study's primary research question. In sequential designs, data are collected and then followed in a subsequent phase with the collection of additional data approach(es). Concurrent designs, on the other hand, are characterized by the collection of all sets of data during the same state or phase. Data were partially mixed, with neither data set dominating the other. This strategy is viewed as optimal for triangulation of complex phenomenon like caregiving and importantly, potentiates findings that are less likely to be an artifact of the method (Creswell, Klassen, Plano Clark, & Smith, 2011). Data was collected to respond to the following:

- How do caregivers of Native Hawaiian kūpuna dwelling in one homestead community perceive their concerns as caregivers?
- What knowledge, attitudes, and resources enable their caregiving? Disable their caregiving?
- How does caregiver knowledge, attitudes, and resources affect the care of Native Hawaiian kūpuna with memory loss, including ADRD?

Understanding the concerns and challenges of caregivers of kūpuna with memory

loss on one Hawaiian homestead is the focus of this study. Over the last twenty years, a number of surveys have been distributed in the community of Papakōlea. Over the years, the best response rate has come from the kūpuna of the community with approximately a 35% rate on the 2008 Kawaihonaakealoha survey until the caregiver survey that has a 43% response rate.

The quantitative arm of the study involved development and administration of a written survey eliciting sociodemographic characteristics, as well as knowledge-attitudes-behaviors on caregiving. The qualitative arm of the study involved focus groups and was intended to clarify and extend information learned through survey data. Specifically, focus groups elicited participants' caregiving experience in the context of ADRD. Our mixed methods design allows us to infer with some certainty the causal factors at play in increasing community support for this population.

Survey. Using a CBPR approach, with the support of community the survey questionnaire for the quantitative study was adapted from five other survey instruments:

1). Homestead Health Survey (2015) consisted of five sections, including questions on: a) Demographics - age, ethnicity, education, income and household size; b) Health Status - diagnosis of hypertension, cancer, diabetes, and other medical conditions; c) Health Behaviors - diet and physical activity; d) Cancer Screening - mammography, Pap ,prostate, and colorectal tests; e) Psychosocial Factors - life satisfaction (2) UH-Kawaihonaakealoha Phase I demographics study (2007), used the "*Identifying Our Needs: A Survey of Elders IV,*" a Nationwide Elder Needs Assessment; a survey of long-term care, a category that includes a range of supportive services and assistance provided to persons who, as a result of chronic illness or disability, are unable to function independently on a daily basis, and can include health promotion, home health services, personal care, housekeeping assistance, nutrition programs, meals-on-wheels, adult day care, skilled nursing care, assisted living, and other in-home services, and is an emerging unmet need in Native Hawaiian

communities.

The Dementia Friendly America Toolkit (2015); the Behavioral Risk Factor Surveillance Survey [BRFSS] Caregiver Module (2015) is a national survey, the BRFSS questions included are the revised 8-item Caregiving module. The State of Hawai'i provides data to Native Hawaiian health organizations, community nonprofits, and ethnic groups for program planning and health advocacy; other reports target different research groups from BRFSS. The Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE, 1994) was used in the survey. The Short IQCODE is a questionnaire that asks a respondent about changes in an elderly person's everyday cognitive function. The questionnaire aims to assess cognitive decline independent of pre-morbid ability. The questionnaire was found to have high internal reliability in a general population sample (alpha = 0.95) and in the dementing sample (r = 0.75), a reasonably high test-retest reliability over one year (Jorm, 1994).

Data Collection. Participants of the study were self-identified current and former caregivers, age 18 and older, experienced in caring for kūpuna with conditions associated with age-related memory loss (e.g., ADRD) and other chronic diseases. Surveys were mailed to 392 lessees of residences in Papakōlea (93%). The response rate of the initial mailing was 22% (n = 85). Snowball sampling was used to canvas community for another 21% (n = 83) for a total response rate of 43% (n= 163). Eight surveys were returned without consent and had to be excluded from count leaving (N=155). Snowball sampling engages participants in identifying other potential participants that are experiencing similar situations. Community Health Workers practicum students and the Community Liaison conducted identified residents. All surveys were received by including community canvassing by April 23, 2018.

Sampling. Papakōlea community members were engaged from the onset of this research process assisting with the development of the research questions, finalization of the research questions, development of the survey questionnaires, testing the survey

instrument, mailing of the surveys and gift cards, and facilitating focus groups. The collaboration with the community will continue through the final report out of findings and dissemination through academic journals. The community will own the data collected from this study.

The literature reviews focused on relevant aspects of ADRD such as historical references, ADRD in community, dementia friendly communities, sociodemographic, caregiver grief/burden, caregiver burnout, and caregiver interventions, and caregiver curriculums. Three types of reviews were conducted, *Narrative reviews* essentially describe relevant literature by topic areas (the Browne et al. article, in the press is an example a narrative review of dementia in the context of Indigenous people). Most of the reviews collected fall into this category (e.g., Benart et al., Browne et al.; Naples et al.); *Meta-analysis* - here, the authors compare the effect size of interventions converging around a similar set of variables (e.g., Brodaty; Sorensen); *Meta-synthesis* –here, the authors review compare/contrast/ synthesize common concepts detected in qualitative studies (e.g., Large & Singer, 2015).

Limits were applied to include adults 45 and over for having ADRD, and 18 years of age and up for caregiving. This age group was selected because ADRD and chronic diseases are more prevalent in older adults in Papakōlea (Homestead Health Survey, 2015). The initial search of databases and websites identified 263 combined sources, including journal articles, book titles, reports, manuals, curriculums, websites, and conferences. The purpose of this mixed-methods study is to explore the perception of needs, and understand the concerns and challenges of caregivers of Native Hawaiian kūpuna or elders (age 55 years and older) with age-related memory loss conditions, specifically, ADRD, on the Hawaiian Homestead community of Papakōlea. Specifically, to understand the experiences of the caregivers and whether community-based support could be provided to help to avoid caregiver burnout and enhance kūpuna care to allow kūpuna to safely age in place.

Quantitative Data Analysis.

Data analysis was conducted using SPSS version 22.0, 2015, for frequencies for categorical variables and means, median, and measures of dispersion for continuous variables. The nominal data and ordinal (financial, physical or emotional burden) variables will be reported if there are significant between-group differences between sub-communities (Kewalo, Kalawāhine, and Papakōlea), sex of caregivers, and income. If not, only demographic data will be reported (Lum, Arnsberger, & Sato, 2010-2012).

Qualitative Data Analysis.

Kula has utilized culturally tailored focus groups for over a decade as an appropriate platform for the query into situations that may be unique in this Hawaiian community due to culturally sensitive approach that can be applied. Following protocols developed by Braun et al. (2006), all focus groups began with pule (prayer), sharing of food, and allowing time to kukakuka (discuss and consult). The participants for the focus group participants were selected from the indication of interest on the mail survey. Two 90-minute focus groups were held on two consecutive evenings in the Papakōlea Community Center Library. Group one had 56% of the participants (n=10), and group two 44% (n=8) was a homogenous male group, total participants (N=18). Caregivers identifying interest in focus group participation were contacted by the Kula No Nā Po'e Hawai'i's (Kula) Kūpuna Community Care Network (KCCN) Program Coordinator. The focus group characteristics (Table 1.).

Combined sample (N = 18)			*Focus Groups*
Ethnicity	**%**	**%**	**%**
Hawaiian	10 (55.0)	8 (45.0)	18 (100.0)
Gender			
Female	9 (90.0)	0 (00.00)	9 (50.0)
Male	1 (10.0)	8 (100.0)	9 (50.0)
Community			
Papakōlea	4(40.0)	3 (37.5)	7 (38.8)
Kewalo	2(20.0)	2 (25.0)	4 (22.2)
Kalawāhine	2(20.0)	2 (25.0)	4 (22.2)
Other	2(20.0)	1 (12.5)	3 (16.6)
Caregiver status			
Current Caregiver	7(70.0)	5 (62.5)	12 (66.6)
Former Caregiver	3(30.0)	3 (37.5)	6 (33.4)
Caregiver 1	8(80.0)	6 (75.0)	14 (77.8)
Caregiver 2 or more	2(20.0)	2 (25.0)	4 (22.2)
Kūpuna w/Alzheimer's	7(70.0)	3 (37.5)	10 (55.5)
Kūpuna w/Chronic Disease	3(30.0)	5 (62.5)	8 (44.5)

Data are *n* (%) or means ± S.D.

Focus group sessions were held in community library/technology center at the Papakōlea Park & Community Center. The researcher identified a facilitator from the community to conduct both focus groups using a prepared moderator's guide (Appendix A). Sessions were audiotaped, and a trained note taker kept field notes to document specific context and non-verbal observations relevant to interpreting the data. Before the group session, a verbal poll was taken to get necessary demographic and descriptive information (e.g., age, the gender of the person receiving care, the homestead of residence) was collected from participants. At the onset of the group discussion, each participant was asked to briefly describe their caregiving experience how they came to participate in the focus group.

Study Design. The qualitative method is used to clarify the findings in the quantitative method of inquiry. A qualitative and inductive methodology was selected as part of this study to explore the perceptions, knowledge, attitudes, and challenges of community caregivers of kūpuna with ADRD and other chronic disease. The use of focus groups allows the opportunity for the "kukakuka" style of sharing information most

comfortable to community members (Browne et al., 2014). Gathering information using a "kukakuka" (talk story) style of inquiry has been successfully utilized by residents with long-standing bonds and relationship in research projects conducted in Papakōlea.

Reviewers extracted themes based on (1) their mention in the focus group, (2) their elaboration or endorsement by other members in the group, and (3) their mention in at both of focus groups. After the reviewers identified themes, they met as a group along with the focus group facilitator and co-facilitator to discuss the identified themes and their placement within the four domains of interest such as health, culture, aging, and families'. Themes that were similar were aggregated into a single representative theme.

Data Collection. Conducting the focus groups after the quantitative portion of the study was important. The process is important to the community. During the literature review found many of the surveys started with the qualitative portion of the study being the first phase of the study to guide the quantitative questions. The focus groups coming after the survey provides the opportunity to discuss the questions. The community needs to understand why specific questions were asked and how their suggestions were addressed. Most importantly, in CBPR at the earliest juncture of research that they have been respected. Once data is in hand, collected. There is a requirement that the researcher reports out to the community.

The report to the community was mailed to the 392 lessees before the doctoral student oral examination. When researching a guest of the community, one must remember the community guides the CBPR process when the community has built capacity. The two focus groups of current and former caregivers of Native Hawaiian kūpuna were convened to complete the objective of this study (N = 18). Focus group one (n =10) seven current caregivers and three former caregivers, one caregiver provide cares for more than one kūpuna. The gender of the group was majority female (n =9) and male (n = 1). Both focus groups were facilitated by Kula staff member that is a resident of the community and

recorded by social work practicum students from the Myron B. Thompson School of Social work.

The second focus group was all male (n = 8) recruitment of men who had indicated that they would be willing to participate in the focus group was intentional. The homogeneous group was conducted to follow-up on some of the concerns of the women of the women of the first focus group. Recruitment for the focus group was conducted by a different Kula staff member than facilitated that is also a community resident responsible overseeing community the outreach for most community programs. Adhering to CBPR principles, the survey/questionnaire, focus group guide, questions and methods proposed for this research was submitted to community leaders for approval before use.

The focus group methodology was employed because it is consistent with the tradition of Native Hawaiians and other Pacific Islanders who prefer to share their experiences orally and face-to-face (versus surveys or telephone interviews), allowing them to judge the researcher's intent and trustworthiness as information is shared. The focus group questions were constructed to answer research question 1) how do caregivers of Native Hawaiian kūpuna dwelling in one community perceive their concerns as caregivers and question 3) How do caregiver knowledge, attitudes, and resources affect the care of Native Hawaiian kūpuna with memory loss, including ADRD and other types of dementia in Papakōlea?

The focus groups took approximately 90 minutes as each person had a lot to share. Before participation, informed consent was given, and participants understood that the researcher cannot control what other participants share outside of the focus group session and, therefore, cannot guarantee confidentiality. In the first focus group, made up of primarily wahine (women) only one kane (man) was present. He arrived late and left early, although he was fully engaged for the time he was there. The women were overwhelmed with the emotion of others, as one cried they all cried, and seem to focus more on the

struggles with the brothers of the family if they had one and the lack of community kuleana (responsibility) for each other as they had grown up together. The changing demographics was a big part of the conversation about taking care of the kūpuna. The questions were drafted and prioritized before the focus group was held. Notes were taken during the focus group, the data collected and analyzed, and the findings will be disseminated. Data from these focus groups were gathered and analyzed to determine the extent to which each participant has been impacted by ADRD and other dementia or their caregiver experience in regards to understanding what type of additional service is needed and how the community can assist in obtaining needed services.

Study Participants. Papakōlea residents that (a) self-identify as a current or former caregiver of a Native Hawaiian kūpuna with memory loss, e.g., ADRD or another chronic disease (b) be ≥ 18 years at the time of the study, (c) express interest in participating. Two focus groups of eight to ten individuals were held. (Maximum n=18). Participants were encouraged to reply to each question but were apprised of their right not to respond or to leave at any time without consequence.

Compensation. Participants received a $10 gift card for returning a completed survey and $10.00 gift card in appreciation for their participation in the focus groups. Kula provided the gift cards.

Data analysis. Content analysis of the data in several stages of transcriptions was read and re-read a number of times for initial or descriptive coding of the transcripts. The researcher and facilitators analyzed focus group data using a content analysis technique. The audio recordings of the focus groups were transcribed verbatim for analysis. The analysis began with a review of the transcripts by three independent reviewers to extract themes across the areas of interest. It was decided to extract and compare focus group themes by groups rather than by individuals because an individual's responses can be influenced by the responses of other group members and not necessarily reflect one's ideas or beliefs.

One of the transcript reviewers was Kula staff who assisted in conducting the focus groups; the other was a community leader who had no involvement in the focus group under review. After the reviewers identified themes, they met as a group along with the focus group facilitator to discuss the identified themes and their placement within the areas of interests.

The transcripts were reviewed and organized content into broad area, and then into thematic categories, e.g., love for the person, multiple caregivers needed, and communication important and most never saw themselves in the role of caregiver, unexpected role. Analysis of transcripts content using an incidence density approach (number of times a theme is mentioned in a group) was done. The researcher of this study independently reviewed the transcriptions to identify themes and classify data for an understanding of the key concepts that continue to emerge throughout the interviews that likely are perceived to be most important in the community.

Initial coding was performed independently by hand among three coders with a focus on key phrases and common themes. Coders then met to review and reach a consensus on all themes and key phrases. Once all data was coded, there was an analysis of data for trends among the various caregivers' responses. The analysis identified key variables, skills needed, acquired, and improved as a caregiver.

Mixed Method Data Integration. Each study phase was analyzed separately as a first step. Data integration is necessary, however, to address the mixed method research question. To achieve data integration, themes were identified for each phase (QUANT and QUAL) and then integrated into final results and implications. Quantitative evidence was interwoven with the qualitative data uncovered in phase two. Some of the former are presented in tabular form while most of the qualitative data are presented thematically. There are instances where data agree and expose other areas of concern. Data exposed challenges and concerns in the area of diagnosing and preparing for the aging population.

Validity. There is selection bias in limiting participation to residents of Papakōlea. There are differences between homestead communities in the expression of Hawaiian values and practices and degrees of community capacity. Therefore, this study may not be representative of all homesteads statewide. Because we will be using key informants and some selection participants' results may not be generalizable within the three communities and other homesteads. The methodology will capture information that is acceptable and relevant. Self-identification of ancestry introduces systemic error. Self-identification varies as attitudes towards Native Hawaiian identification have changed over time. Researcher bias is inherent in the framing of the interview questions.

The credibility of the research will take into consideration the relationship that already exists with many of the participants and the likelihood of their being candid in the interviews and having access to having participants' input on accuracy before finalizing data. Seeking the support of "key" community leaders in how to ask questions in a culturally appropriate manner will also help to get responses that are more honest.

In Papakōlea, they allude to the "community speak" acknowledging that certain community leaders are gifted at communicating with this population, especially those in their later years, and support was available if needed. There was a concern that residents would not be candid. However, the rapport established at the onset of the interview reinforced the responsible use of information to inform the process, which should alleviate the need to subvert candor. Despite these many limitations, there is interest in and value to a descriptive study to validate capacity and readiness for program participation in homesteads.

Reliability. The researcher's relationship with "key" community leaders was useful, as they will assist in approaching the residents for participation. Therefore, there would be minimal challenges to data collection as long as it is appropriately done, acknowledging the

community as owners of all data collected, which is required when researching Papakōlea. Possible researcher bias can be addressed through keeping track of emotional attachments to some of the residents.

The past and current work of Papakōlea in addressing health for its members will allow participants to share in the manner that is comfortable to capture the type of information that is needed. This study in Papakōlea its broadest conceptualization is intended to inform other Native Hawaiian Homestead organizations in the State of Hawai'i community capacity building to support kūpuna aging safely in place.

There is a growing body of research into indigenous people, however, few have focused on Native Hawaiian Homestead communities. Focusing on one community may limit the generalizability of the study. However, there may be similarities between Papakōlea and other homestead communities that may be explored in future studies.

Researcher Bias. A unique relationship between the researcher and participants already exists. Based on these relationships, there is a likelihood of candor in the interviews and having access to having participants' input on accuracy before finalizing data. This process should include provisions for assuring that responses to questions have no impact on current or future program participation or service delivery.

Ensuring that trust of the community and the relationships that exist are not compromised requires that there is purposeful intent to maintain the confidence of the community. The relationship with "critical" community leaders was useful, as they will assist in conducting the consent process and focus groups. Therefore, there would be minimal challenges to data collection as long as it is appropriately done, acknowledging the community as owners of all data collected, which is required when researching Papakōlea. Possible researcher bias can be addressed by following the cultural safety practices that Papakōlea and other Hawaiian communities have acknowledged in previous studies (see figure 4).

Having participated in current work of Papakōlea in addressing health for its residents ensuring this cultural safety praxis is adhered to will allow community share in the manner that is comfortable to capture the type of information that is needed. Researcher bias and reflexivity present limitations to this qualitative methodology. This researcher is of African American descent and has worked in the community for approximately 23 years. Therefore, there exists personal bias, positive and negative feelings connected to ADRD, and preconceived notions. To keep this bias in balance, the researcher documented field note memos through the data gathering process and sought feedback from other community members to validate coding and conclusions. Focus groups were audiotaped and transcribed for reiterative examination of the data.

Focus groups have been used in research in Papakōlea. The purpose of the previous focus groups was to gather qualitative data about the ideas, concerns, and perspectives of community members regarding issues in their community; therefore, there is already a comfort level in participation by many residents (Mau et al., 2010). In a study on cancer in another Hawaiian community, participants confirmed the importance of recognizing and incorporating Hawaiian cultural values and practices in research, researcher conduct, cancer education, and community events (Braun, Tsark, Santos, Aitaoto, & Chong, 2006).

The use of CBPR will support the premise that as communities play a more active role in research, they will gain essential skills in identifying problems/issues and addressing those using appropriate solutions, specific to their communities. In doing so, they will become more empowered. This research study will provide information that may be integrated with current kūpuna program activities that support kūpuna with ADRD or dementia and may inform future project efforts.

There was concern when sending out the current caregiver survey whether the kūpuna survey will impact the response rate since many of our caregivers are 55 and older.

This mixed methods research study used both quantitative (survey) and qualitative (focus groups) studies to collect data to inform the cultural tailoring of an intervention. Cultural tailoring takes into consideration the intervention educational materials must be relevant to the targeted culture incorporating their terms, customs, and practices (Ka'opua et al., 2014). The study focuses on identifying the needs, knowledge, attitudes, and resources that enable or disable caregiving, with a view toward informing care within the homestead community.

In 2015, the kūpuna of Papakōlea continues to be the most engaged in community. The surveys conducted in community indicate that the kūpuna have high response rate and use more of the interventions than any other population. Kūpuna access services from Na Lomilomi O Papakōlea, KaHolo Study, KCCN Workshops and Holo Holo. The ability of the community to begin to understand the impact of the numbers of the Homestead health survey. Acknowledging the need to embrace the CBPR process to work on the quantitative survey we began with a discussion with community leaders to have a conversation when the dissertation topic changed from community resilience. The majority of the Kula staff have been the caregivers for their loved ones over the last five years. Therefore, the input on the questions and issues that should be considered were welcomed.

Community Investigator. It has been over a decade since the conversation about having Community Investigators for research at the grassroots level. Conversations began as CBPR helped to build our capacity. Starting with the PILI ʻOhana intervention the talk of the community investigator one day having the capacity to apply for an R01 grant from the National Institute of Health to continue to build the capacity of community. Papakōlea has served as research site for many different researchers over the years from Nursing to Social Work. Now, at the end of the journey community will begin to define the role of Community Investigator determining what that position will entail in community.

Researcher. This idea of this research engaged community leaders at the onset of

the academic journey of the Ph.D. student as is merited in the CBPR approach. Initially, the original research topic agreed upon by community leaders was Community Resilience, however, after attending the Inaugural Conference on Alzheimer's and Dementia in Native Communities in Phoenix, Arizona in October 2015, permission was obtained to change the topic.

Emergent Role. Caregiving for family members with ADRD can be thought of as an emergent role, one neither anticipated nor entirely prepared for before acceptance of the position. Being unaware and unprepared to be an immediate caregiver comes with an expectation of stress. There is a way that people come to adjust to handle or not handle the stresses of life (National Institute on Aging, 2010).

We often hear reference to how one can handle or cope with those problematic life situations we must face across our lifespan from birth to the death. The needs of kūpuna in the community are becoming more apparent the more that we engage in service learning. It is crucial that we get the additional information needed so that resources that will support the kūpuna and ʻohana are obtained before there is a family crisis. The community would like to be more proactive in meeting the needs of kūpuna who want to age in place.

This process began with asking permission of the community organizations to conduct a study in a community with the understanding the doctoral student must lead the project which would be somewhat of a change for the community. Community leaders have grown accustomed to taking the lead in most of their previous research. Therefore, a request to support this study and consideration to culturally tailoring the dementia friendly toolkit if supported by research findings was submitted to the Kula, Papakōlea Community Development Corporation (PCDC), Kewalo Community Hawaiian Homestead Association (KCHHA), and the Kalawāhine Streamside Association community-based organizations.

All organizations voted to approve the request and PCDC, Kula, and KCHHA provided letters of support and commitment to the study. The CBPR approach allowed for the community to be engaged to:

- provide guidance in the development of research questions
- participation in key informant interviews,
- provide social and cultural context as needed
- assist with community mailing to include coverage of cost,
- assist with data entry of survey information,
- facilitation of focus group,
- assist with data analysis of focus groups; and
- provided gift cards.

Caregiving is not a solitary function. What is clear from the data collection is that there are many levels to providing care. One moves in and out of roles. The increase in the aging population moves one in and out of a macro positioning. There is work to be done at every level. Providing safety for a kūpuna with ADRD requires that personal space and dignity be provided throughout the disease.

There are many instances where the stress causes the caregiver to become a patient if it is only temporary when a respite is long overdue, and the body gives way to the stressors. Another level of family or community is then required to step in, now there is care needed by more than one, and the support system of each patient must take part in the care. Long-term care only becomes more complicated by a kūpuna who has worked hard to isolate themselves. Slowly they will be placed in a position when there are no longer trusted with their care and assistance is warranted. The following figure outlines the process taken when working with the community on this study following the CBPR process in place in Papakōlea. Working with the community was very important from the initial concept of the dissertation that started out as a different topic, to the change in topic, to address an identified and growing concern of the community. Community leaders not only approved the research topic but also provided input on the questions. Additionally, community leaders were included in a discussion on research methods to be used and the development of the survey tool.

CBPR in Papakōlea Study Process

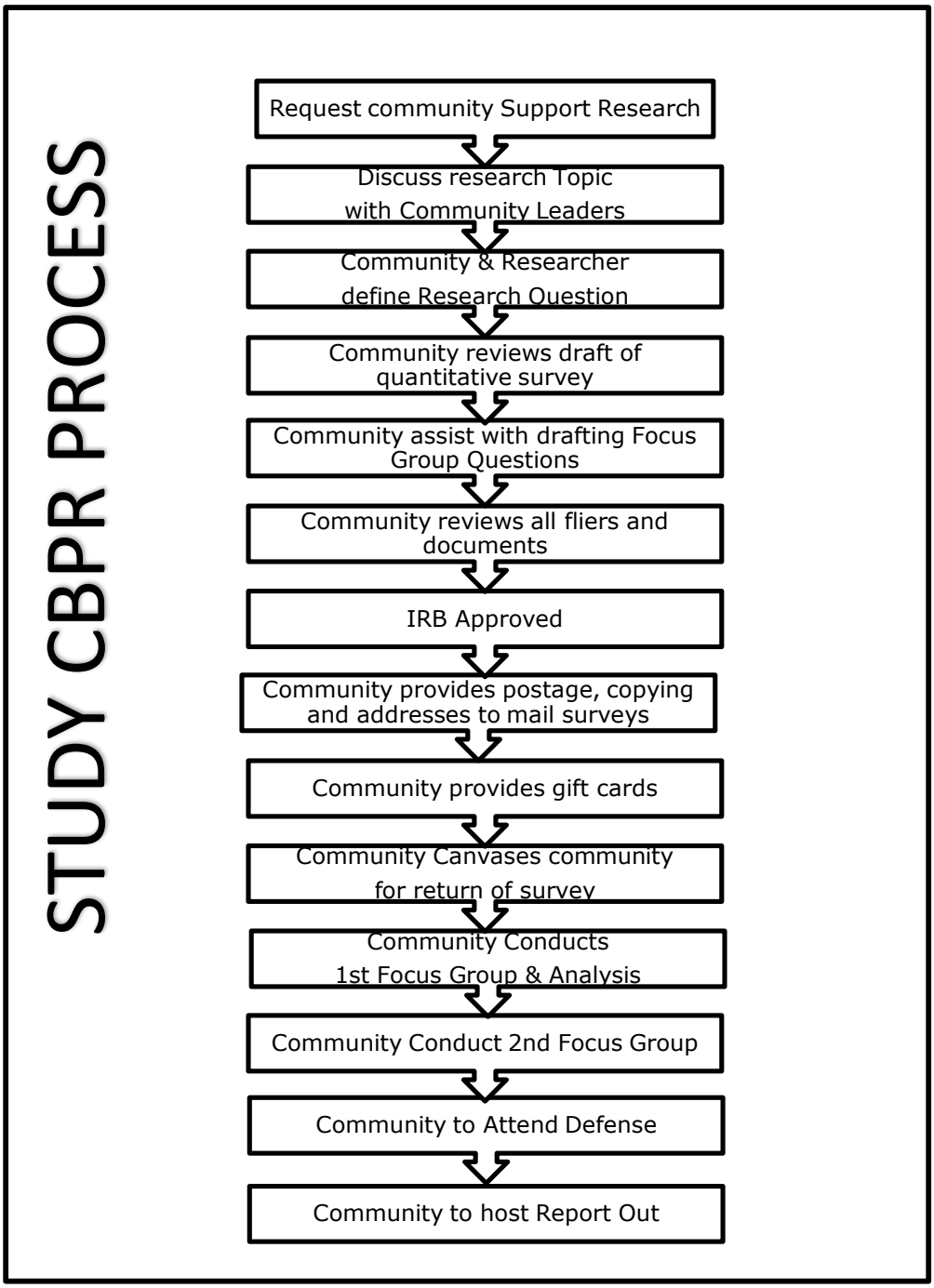

Figure 6. Research Study CBPR Process

The resources within the community and strengths of these resources are considered in CBPR. The research model identifies the support to the social structures and processes (US Department of Health and Human Services, 2003).

The CBPR research approach improves the direction and definition of research as both researchers and community work in close collaboration to understand the underlying research purpose (Polanyi & Cockburn, 2003). Research has greater benefit when there is understanding of the cultural context in which research subjects exist and a desire to use research findings for the betterment of participants. This exists in this research process. Community leaders tested the survey tool once completed for ease of use providing the approval and resources to mail to the community.

Historically, these incredible women set the bar in how Papakōlea supports healthcare today, and they have successfully cultivated an expansive network, as well as the next generation of impassioned leaders, as creative initiatives continue to roll out.
Today, organizations operating out of the Papakōlea Community Center looks to a number of different options to provide care. This was instilled in workers who have had the opportunity to be mentored by the organization founders. The control of the community center was returned to the community in 2002. In 2009, the community began to work with the Department of Hawaiian Home Lands and their regional plan. Papakōlea has the advantage of having many community organizations working towards the benefit of the people. These community organizations have a variety of programs geared toward youth empowerment and development, community mobilization, cultural activities, and health and wellness. Programs such as these are vital to the community's well-being. They continue to strengthen individuals, as well as the collective community of Papakōlea.

Evidence-based and culture-based psychosocial programming in dementia care for indigenous populations in the United States should be designed by the communities they intend to serve (Browne, Ka'opua, Jervis, Alboroto, & Trockman, 2016). These communities may offer kūpuna and families the best potential for care that is accessible, respectful and

utilized. Further, rather than focusing on a western approach to training in a classroom with textbooks, practitioners use a relationship-based approach to building trust first (Browne, et al., 2016). Once a relationship is built, and trust earned, the community will allow the provision of healthcare services. These efforts have resulted in a host of successful collaborations that provide the foundation for Papakōlea's approach in program design and delivery.

The concept of designing a cultural program within the walls of a western system promotes an incredible culture of creativity. It challenges collaborators to look beyond current offerings, to provide families with uniquely tailored services, experiences, and opportunities. To gain a greater understanding of Papakōlea's perspective, one must first understand, that everything is founded on aloha (deep unconditional love) – aloha for ʻāina (land), aloha for the community, and aloha for ʻohana. As a people, Native Hawaiians have a deeply rooted connection to their ʻāina (land). Aloha ʻāina represents a basic expression of the Hawaiian experience. For Native Hawaiians, the ʻāina sustains the identity, continuity, and well-being as a people (McDermott & Andrade, 2011). Partnerships garnered are centered on aloha of this place, and service to its people.

In Papakōlea, walls are symbolically removed, having the benefit of having many organizations working for the advancement of community, and generations to come. These organizations support a variety of programs focusing on youth empowerment and development, community mobilization and participation, cultural activities, and health and wellness. Programs such as these are crucial to the community's well-being. Connection with the community and traditional Hawaiian values of working together, with less of a focus on individualism is a strength to the development of Papakōlea. Showing reverence for shared cultural traditions and values, and identifying with others in the community because of this shared history, has provided Papakōlea residents with something to identify with, and a greater sense of belonging. (Kula No Nā Poʻe Hawaiʻi, 2016).

This place-based model of program delivery is advantageous because it is a culturally relevant method for executing services in a Native Hawaiian community and will continue to strengthen individuals, as well the collective community of Papakōlea. It requires community leaders to be creative and swift while overcoming the social, economic, cultural, environmental, and physical barriers to accessing and receiving adequate health care services.

Rather than providing training at a medical clinic, medical professionals, academia, community volunteers, students, and residents, extend their reach beyond the walls of their offices, and service families in their home, Papakōlea. Further, rather than focusing on a western approach to training in a classroom with textbooks, practitioners utilize a relationship-based approach to building trust first.

CHAPTER 3. RESULTS

The notion of caring for kūpuna and allowing them to safely "age in place" is a cultural norm amongst Native Hawaiians. However, services that foster independent, safe and healthy living, are unaffordable for many kūpuna and their families. Further, the families are not equipped to care for their kūpuna diagnosed with these chronic diseases, due to lack of access to information, education, and training. Moreover, increased caregiver stress results in the placement of kūpuna in long-term residential facilities. In 2030, it is anticipated that 40,000 of kūpuna will need long-term care, and Hawai'i's facilities will only be able to serve 30% or 12,000 kūpuna. To adequately support the remaining 38,000 kūpuna, government agencies and private corporations will have to rely on non-profit organizations to serve the remaining 70% to safely "age in place.

The results of the study with emphasis on current and former caregivers of Native Hawaiian kūpuna with memory loss on the Hawaiian Homestead community of Papakōlea is after conducting mixed methods study to determine how caregivers of Native Hawaiian kūpuna dwelling in Papakōlea community perceive their concerns as caregivers; speaks to the concerns raised by the caregiver of community via the quantitative data and qualitative data.

There were 163 surveys returned to the Kula P.O. box. Once received the surveys were date stamped by staff twice a week before data entry. Surveys without a consent form were tracked and entered into data the system, but not included in the data analysis. A field was added to data system to verify whether consent was received; email address was saved, if available. There were 155 surveys received. Surveys were received via mail, dropped off at the community center, or retrieved residents' homes. Once the gift card was returned, the data entry was conducted using google forms to enter each survey field,

Additionally, a field was added for the respondent to indicate whether there was interest in participating in the focus groups held at a later date. The quantitative survey was

mailed to 392 homes, for the statistical power needed 150 surveys. The response rate for surveys was 40%. Survey data were entered within one day of receipt using Google Forms. After entry, data was cleaned based on data codebook guidance for research assistants. Data was cleaned and tracked on an excel spreadsheet before loading into SPSS version 22.0, 2015. The Program Coordinator, Kula, and social work practicum student from the Myron B. Thompson School of Social Work were responsible for the quality assurance of data. Data were coded for entry and analysis using dichotomous codes (e.g., 1=female and 2=male). Demographics, Kūpuna Demographics organized the survey instrument. The study determines there were more kūpuna who have access care in the past or are currently accessing care in the community.

Table 3. ADRD CAREGIVER/KUPUNA
Age, Ethnicity, Gender, Relationship, Sub-Community, # Co-morbidities

	CAREGIVERS	KUPUNA	CARE	RECIPIENTS
AGE	18-25	6 (12%)	55-65	1 (2%)
	26-35	8 (16%)	66-75	5 (10%)
	36-45	4 (8%)	76-85	12 (24%)
	46-55	11 (22%)	86-95	18 (36%)
	56-65	11 (22%)	96 and over	10 (20%)
	66-75	8 (16%)		4 (8%)
	76-85	2 (4%)		
		(4%)		
ETHNICITY	NATIVE HAWAIIAN (YES)	45 (90%)	NATIVE HAWAIIAN (YES)	47 (94%)
GENDER	GENDER (FEMALE)	37 (74%)	GENDER (FEMALE)	40 (80%)
COMMUNITY	PAPAKŌLEA	32 (64%)	PAPAKŌLEA	36 (72%)
	KEWALO	7 (14%)	KEWALO	8 (16%)
	KALAWĀHINE	5 (10%)	KALAWAHINE	1 (2%)
	OTHER	1 (2%)	OTHER	5 (10%)
	BLANK	5 (10%)		
KUPUNA REL.			MOTHER	19 (38%)
TO CAREGIVER			FATHER	6 (12%)
			MOTHER-IN-LAW	4 (8%)
			FATHER-IN-LAW	1 (2%)
			GRANDPARENT	15 (30%)
			NON-RELATIVE/ FAMILY FRIEND	5 (10%)
CAREGIVER				
HOUSEHOLD SIZE	1	2 (4%)		
	2	5 (10%)		
	3	8 (16%)		
	4	4 (8%)		
	5	8 (16%)		
	6-10	17 (34%)		
	11 or more	4 (8%)		
CG HOUSEHOLD INCOME	15k - 20k	3 (6%)		
	25k - 35k	6 (12%)		
	35k - 50k	9 (18%)		
	50k - 75k	10 (20%)		
	75k or more	12 (24%)		
Current or Former Caregiver		50 (100%)	Kūpuna Care Recipient	

Table 4: Sub-Community, Annual Income, Age, Gender and Ethnicity N=155

Community		*Annual Income*		*Respondent Age*		*Gender*		*Ethnicity*	
Papakōlea	99 (68.3%)	Under 10K	6 (4.0%)	18 - 25	12 (7.8%)	Male	55 (35.5%)	Hawn	143 (92.3%)
Kewalo	24 (16.6%)	10K – 15K	6 (4.0%)	26 – 35	20(13.0%)	Female	100 (64.5%)		
Kalawāhine	21 (14.5%)	15K - 20K	8 (5.4%)	26 - 45	18 (11.7%)	Trans			
Other	1 (.7%)	25K – 35K	15 (10.1%)	46 - 55	29 (18.9%)				
		35K – 50K	23 (15.4%)	56 - 65	37 (24.0%)				
		50K – 75K	21 (14.1%)	66-075	29 (18.9%)				
		75K or More	43 (28.1%)	76 - 85	9 (5.8%)				
		Don't Know	27(18.1%)						
Totals	145*		149*		154*		155		143*

* Total =155- "99-unaswered"

Approximately 92% of participants identified as Native Hawaiian (n=155). Age ranged from 18 to 82 years (*M* = 51.22, *SD* 16.347). Per respondents, 48% (n=42) of the kūpuna have been diagnosed with an ADRD and 54% (n=49) believed that they cared for someone with an ADRD, despite the elders not receiving a diagnosis from their physician. Kūpuna age ranged from 55-96 and over. Close to ⅞ of Kūpuna were between age 76-95.

Results of this study indicate that current and former caregivers provided care primarily to their mothers 41% (n=48), fathers 11% (n=13) and grandparents 21% (n=25). Research has found a secure connection between caregiver stress and an elder's move to institutional care, indicating that families who are unable to access aging-in-place services to manage their stress are more likely to move their elders into nursing homes which cause an additional hardship of Native Hawaiian families who have been taught that it their kuleana (responsibility) to care for their kūpuna (Caring for Kūpuna, Hawai'i Community Foundation, 2013).

There is a need in many communities to understand the increasing demands of the aging population with significant memory loss due to age to include disorders classified

under Dementia such as AD and other related conditions that affect cognitive functioning. Many families and communities are not prepared to manage the challenges being faced by this population. While mild forgetfulness can be a normal part of aging, it can also be a sign of more serious memory problems, such as amnestic mild cognitive impairment, dementia, or even Alzheimer's disease. It is highly unlikely that many in our communities understand the difference between normal age-related changes in memory and abnormal changes that indicate conditions such as dementia may be present (National Institute on Aging, 2016).

Hawai'i's kūpuna needs to be connected to a community. In a survey of seniors in Honolulu County, 45% of respondents said isolation and loneliness affect their quality of life. When asked, "What services do you need that are not available in your community?" 40% of respondents identified senior center activities. 17 Connection to peers, to the community, to culture, and to meaningful activities offers a sense of purpose to individuals of all ages and especially to kūpuna. When seniors are not connected to the community, no one is aware of these challenges and can offer help (Caring for Kūpuna, Hawai'i Community Foundation, 2013).

Many of the homes of Papakōlea are multi-generational. The most commonly reported health conditions for kūpuna were: heart disease/hypertension (54%) and ADRD (45%). Four participants reported caring for a kūpuna with a dual diagnosis of stroke and vascular dementia. 39% of caregivers provide care for more than five years with 60% residing with the care recipient. Providing personal care for kūpuna in the last 30 days is a predictor of whether or not the kūpuna has been diagnosed with dementia. The first six months of care for a kūpuna with ADRD according to the data is the most stressful time and when one is more likely to experience burnout due to lack of knowledge on how to care for a person with ADRD and the necessity for self-care.

Table 5. Caregiving for Kūpuna and Types of Services

	Coefficient	Standard Error	Odds Ratio	95% CI Lower Limit	95% CI Upper Limit	p-value
(Intercept)	-0.026	1.0556	0.9743	0.123	7.713	0.98
Length of Time		Reference: < 2 years				
2 years < 5 years	1.1937	0.868	3.2993	0.602	18.082	0.169
More than 5 years	-0.8183	0.6965	0.4412	0.113	1.728	0.24
Enjoyment	0.0017	0.0389	1.0017	0.928	1.081	0.965
Care Provided		Reference: No				
Personal Care	1.985	0.8523	7.2789	1.369	38.688	0.02
Household Tasks	-2.0315	0.8335	0.1311	0.026	0.672	0.015
Outside Services	-0.0805	1.0026	0.9226	0.129	6.584	0.936
Access to Services	-0.31	0.7699	0.7335	0.162	3.317	0.687
Support Group	-0.3278	1.0513	0.7205	0.092	5.655	0.755
Arranging Respite	2.7865	1.3941	16.2238	1.056	249.348	0.046

Dependent variable: diagnosis (dementia) - Independent variables:
Length of time (#18), Enjoyment (#16), Care provided (#20) - Number of Observations = 75

With the other independent variables were controlled for, providing personal care for kūpuna (such as giving medications, feeding, dressing, or bathing) in the last 30 days was associated with a 7.3-fold higher odds of their kūpuna having been diagnosed with dementia compared to caregivers who didn't provide personal care (p >.02) in the last 30 days, arranging respite p-value <.05 is considered significant, and highlighted in yellow (excluding intercepts). All other variables controlled for, providing household tasks (p-value <.05 is considered significant, and highlighted in yellow (excluding intercepts)) for kūpuna (such as cleaning, managing money, or preparing meals) in the last 30 days was associated with a 7.7-fold (i.e., .13/1.0) lower odds per unit change of their kūpuna having been diagnosed with dementia compared to caregivers who didn't provide household tasks care in the last 30 days.

The current and former kūpuna receiving care somewhat evenly distributed across age

groups starting at age 55. Most are female living in the sub-community of Papakōlea, then Kewalo and Kalawāhine respective (Table 8).

Table 8: Kūpuna Demographics by Sub-Community N=119

Community		*Kūpuna Relationship*		*Kūpuna 's Age*		*Gender*		*Ethnicity*	
Papakōlea	82 (71.3%)	Mother	48 (41.4%)	55 - 65	12 (7.8%)	Male	29 (18.7%)	Hawn	117 (94.0%)
Kewalo	15 (13.0%)	Grandparent	25 (21.6%)	66 – 75	20(13.0%)	Female	88 (64.5%)		
Kalawāhine	7 (6.1%)	Other Relative	5 (4.3%)	76 – 85	18 (11.7%)	Trans			
Other	11 (.7%)	Hanai Relative	1 (.9%)	86 - 95	29 (18.9%)				
		Father	13 (11.2%)	96 and over	37 (24.0%)				
		Mother in law	9 (7.8%)						
		Father-in-law	2 (2.0%)						
		Husband	5 (4.3%)						
		Brother/Sister	7 (6.0%)						
		Same sex partner	1 (1.0%)						
Totals	115*		109*		116*		117*		117*

The number of respondents who identified they were current and former caregivers of kūpuna is 119. Caregiver attitude is measured by their enjoyment and type of care that is enjoyed. The most enjoyment comes from the time spent and companionship (Table 9).

Table 9. Caregiver Enjoyment

	Coefficient	Standard Error	95% CI Lower Limit	95% CI Upper Limit	p-value
(Intercept)	19.4425	1.5105	16.482	22.403	0
Caregiver Role	Reference: Other or Multiple Roles				
Primary Caregiver	0.6318	1.8544	-3.0027	4.2662	0.734
Secondary Caregiver	1.2363	1.9646	-2.6143	5.0869	0.5305
Kūpuna Relationship to Caregiver	Reference: Other				
Mother	-1.6193	1.7522	-5.0535	1.815	0.3575
Grandparent	-1.4171	2.145	-5.6212	2.787	0.5102

In an age-friendly Native Hawaiian community, kūpuna living with chronic disease should be able to have autonomy, high quality of life, and be engaged with their community. The right community services and supports make this possible by taking a "whole person" or person-centered approach that helps kūpuna and their caregivers live meaningful lives and reach their full potential. Most caregivers have been providing care for more than five years with the primary diagnosis being hypertension and then ADRD. Some kūpuna are being cared for with co-morbidities. The implementation of a culturally appropriate intervention that will help to serve kūpuna and their caregivers is most appropriately done at the community level. Native Hawaiians, the dominant ethnic group in Papakōlea, are known to have a high incidence of some cancers, diabetes, hypertension and several other chronic debilitating illnesses. Further, Native Hawaiians also have the shortest life expectancy of any ethnic group in the country.

In Native Hawaiian communities, it is culturally appropriate to care and support kūpuna that wish to age in place. However, families have voiced concern that they are not equipped to provide their kūpuna with quality care to "age in place." It is imperative that families be provided the tools needed to provide quality care for their treasured kūpuna in their homes and community. The need for family conversations was identified in both focus groups, with the consensus on family discussions on advance health care directives need to be held before a medical emergency arises. Participants indicated that conversations should include all family members and that all family members should as much as possible, respect the decisions of their kūpuna. Succession of leasehold property on the homestead was also identified as a crucial issue for family discussion.

Table 11. Focus Group Themes *Focus Groups N=18*

Domains and themes	Representative quotes
COMMUNICATION	**"...**Would be will to come to a support group for men and women and willing to help recruit people from the community who need to be part of the conversation…" need to plan ahead of time and start the conversation early
SUPPORT GROUPS	"Would come to a community only, mixed M/F support group" Need to be able to talk story with others. Many going through the same thing… Learn as you go when caregiving…"
COMMUNITY PUBLIC SERVICE ANNOUNCEMENTS	"…empower families to have the conversation earlier, so much pilikia, and need education tools in the community so kūpuna can make up on mind and plan…"
COMMUNITY KULEANA	"….community should know who is homebound and needs respite…be proactive to determine people that people know…give tips and advice… everyone has to react…disaster recovery…"Getting access to services - where to start?
HEALTH/DEMENTIA LITERACY	"…comforting to know you are not the only one going through…learned a lot tonight…" Informational supports – need One stop, overwhelming go to office browsers, looking for services, navigators
NEED COMMUNITY SUPPORT	"…Outside services - how to get access? Community helps with services…No longer about "me," about "us." Respect…"
GENDER ROLES	Women tend to be natural caregivers; Men have trouble communicating, Men are in denial, Kūpuna gets angry, cuss - hard to help, Hard to provide feminine care for both CG and kūpuna - especially for Mom Role reversal - kūpuna raised them, now CG is taking care of kūpuna
NEED TO COMMUNICATE	"…Brothers and sisters - everyone must step up and pitch in…" "Kūpuna still need interactions/ socialization. Need a checklist to keep up with the opportunities as you learn about it – learned from someone about VA benefits was able to get Dad hearing aid that is hard to get…"
RESPITE/SELF CARE	"…Self-care - have to take care of self to take better care of loved one…" CG is working a full-time Tough job - work all day, go home, then work all night"…Help each other out…need support group, mental & physical respite/support networks…share information
FAITH	"…Had own plans, now following God's plan to care giving Hawaiian thing…" The family has to work together. Never imagined they would be in the CG position
LOVE	"…Do what you must because you **LOVE** them…Need to make the time Go above and beyond Must want to CG, not because you have to…"
DIGNITY	"Hard to see a decline – Denial…Kūpuna was fully active, independent → loss of… Kūpuna was a leader, take charge type…Kūpuna is hard-headed, stubborn, gets angry, spiteful CG still wants to leave kūpuna with **dignity** - if you take that away, they have nothing…"

Content analysis and summary. Transcript reviewers were the focus group facilitator, recorder, and the researcher. The mention of the theme by more than one participant in both groups were given priority. The researcher and facilitators analyzed the focus group data using content data analysis. The recordings of the focus groups were transcribed verbatim by the researcher for analysis. The analysis began with each of four reviewers conducting an independent review of the transcripts to extract themes across the two focus groups on the domains of interest such as health, culture, aging, and family. The reviewers compared themes (e.g. communication, support groups, finances) emerging from transcripts. Reviewers noted the frequency of these themes. Themes that appeared four times were set aside for further comparison.

The themes were randomly list and are not ranked in any type order.

Summary of Preliminary Findings Based on the PEN-3

Theoretical Constructs	*Preliminary Findings*
Perceptions (PEN-3)	Positive • Caregivers for other conditions not just ADRD • Multiple caregivers in many homes • Knowledge regarding the importance respite Negative • Limited knowledge on ADRD • Limited knowledge on personal care • Many brothers not stepping up to assist sisters
Enablers (PEN-3)	Positive • Trust in some community-based organizations, local churches, and community health workers Negative[a] • Cost • Providers don't provide care information • Insurance does not cover everything • Caregiver life on hold
Nurturers (PEN-3)	Positive • Cultural norms to have community support neighbors watching out for each other • Native Hawaiian multi-generational household all involved in care Negative • New to community does not know their community kuleana (responsibility) • Opposition from elderly spouses who want to be primary caregiver •
	Positive • Spouses are caregivers because of love and marital duty • Parents are the best to select before they are sick Negative • Often not diagnosed immediately or until crisis hits – caregiving immediate • No cure for ADRD • ADRD is fatal

Figure 7. PEN-3 Model Papakōlea Focus Group

The PEN-3 Model helped to put the content analysis into cultural context. Many of the participants spoke of the extended family and neighbors being a part of the caregiving team.

Socio-Ecological Theory	PEN-3 Model Cultural Identity	PEN-3 Model Relationships & Expectations	PEN-3 Model Cultural Empowerment	Focus Group Response
Individual, Interpersonal, Organizationss, Community, Public Policy	Person	Enablers	Negative	Hard when caregiver works all date and has to provide care all night
Individual, Interpersonal, Organizationss, Community, Public Policy	Neighborhood	Nurturers	Positive	Multiple Caregivers Needed – not all sibling step of and some feel like they are being taken advantage of.
Individual, Interpersonal, Organizationss, Community, Public Policy	Neighborhood	Perceptions	Positive	Need to obtain outside services – community to help with services.
Interpersonal Organizations	Extended Family	Nurturers	Positive	The family needs to understand the kūpuna's needs need to come first.
Individual, Interpersonal, Organizationss, Community,	Neighborhood	Perceptions	Positive	Caregiver's need self-care
Individual, Interpersonal, Organizationss, Community	Neighborhood	Perceptions	Positive	Learn as you go when caregiving; stay ahead of the game; gets more comfortable over time; trial and error
Individual, Interpersonal, Organizationss, Community, Public Policy	Neighborhood	Perceptions	Positive	Need community support; talk story health each other out; comforting to know not only one caregiving

Figure 8. PEN3 -Model for Caregivers

The ecosystemic view of individuals is embedded in a web of complex, interacting relationships from the individual, interpersonal (family and friends), organizations, community, and public policy. Understanding the concerns of caregivers their responses were categorized by the categories and according to the PEN-3 model for a better understanding of roles and responsibilities. A support group will be implemented as one of the interventions to be offered by KULA, additionally, other community education will be offered by other university partners.

CHAPTER 4. DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

The preliminary findings of this study suggest there is work to be done to support the caregivers providing care not only to kūpuna with ADRD in Papakōlea but also to those with cancer, stroke and other impairing chronic diseases that had not been considered as needing additional caregiver support in the community. The research data suggests it is difficult to determine the numbers of those who need long-term care; different sources use different definitions of functional incapacity and use different data collection methodologies. In anticipation of long-term care bed shortage, there is now a focus on the increasing number of older adults within the U.S., many of whom reside in non-institutional settings. Depending on the number and type of functional disabilities one experiences determines the type of services needed and those needing community-based long-term care varies. The following statement from Brody (1977), made almost 35 years ago, is still true:

Distinctions are blurred, and different institutional names mean different things to different people in different places at different times. A few of the names used in referring to institutions that provide long-term care are homes for aged, homes or hospitals for chronically ill, nursing homes, geriatric centers, rehabilitation hospitals, county homes, veterans' homes, and psychiatric hospitals.

Caregivers in Papakōlea made several recommendations to support aging in place:

(1) Culturally tailor toolkits with particular attention to the use of DFA concepts,

(2) Provide education on the top 10 warning signs of dementia, and

(3) Ensure that CHWs receive Dementia Friends training.

(4) Convene caregiver support groups

(5) Provide respite support

(6) Dementia literacy

(7) Community Health Workers (CHWs) trained as Dementia Friends

There is a need for social workers and certified community health workers in the community to help address the findings of the survey.

The KCCN will implement toolkits, convene support groups, provide education on dementia and train CHWs. Additional follow-up will be conducted to determine what type of DFA toolkits are most needed. The implementation of the support group is currently being planned for once a month. Dementia literacy will be addressed through the piloting of the Savvy Caregiver Curriculum which is being culturally tailored for the Native Hawaiian population. Two CHWs for the upcoming graduating class will be hired to be trained and start in community in July 2018 to assist with home visits that will allow caregivers respite during the week.

Study results suggest that DFA concepts such as educating the community on the top ten warning signs of dementia may be important to deploy. Future research will focus on clarifying and prioritizing specific DFA concepts to address in a DFA toolkit specific to the needs of Papakōlea residents is needed. Specification of key concepts will occur through community discussions that allow residents to plan needed interventions. Kula will design a Community Outreach Strategy for the culturally tailoring of the DFA toolkit that ensures information is shared with all homesteaders in a comprehensive multi-faceted approach.

This strategy shall be based on best practices experienced by Kula in deploying previous health care programs and services in Papakōlea. The steps to defining the Strategy, shall include: 1) brainstorming the outreach activities; 2) defining a public outreach objectives and schedule; 3) identifying appropriate outreach methods; 4) developing clear and consistent messages that align with community values and project outcomes; 5) evaluating and incorporating feedback from outreach activities; and 6) Providing an opportunity for community review of any draft plan, project or report, to maintain credibility, transparency, and relevance.

Tools used to deploy the Community Outreach Strategy shall include the distribution

of flyers, brochures and registration forms at all community events that occur at the Center. Kula manages a mailing list of all households within the homestead community and its project stakeholders. Kula distributes flyers, registration forms, newsletters, and final reports, to all 435 households in Papakōlea, recruiting participants and reporting project progress, via direct mail, mass e-mail announcements, Kula's website, and social media (Facebook).

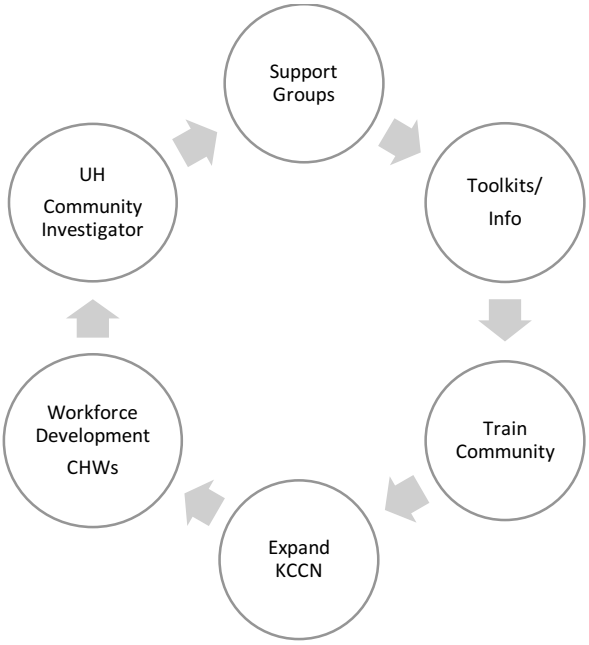

Figure 9. Next Steps

When using a CBPR approach, there is an expectation that data will be used for the betterment of the community. There needs to be tangible action when data has been collected. It is important for research to benefit the community and not be for the sole benefit of the researcher. This study of caregivers in Papakōlea will help the community with their Kūpuna Community Care Network informing organization leaders of caregiver needs. The recommendation is for the implementation of the upcoming phases of KCCN to provide intervention.

Long-term care is one area that requires continuous research to determine appropriate actions to be taken by community. Appropriate community engagement and tailored support of family caregivers have the potential to improve caregivers' experiences

enhancing the quality of care provided to older adults and reducing the use of unnecessary services. Families need to begin having conversations early that address the quality of life and facilitate a shared decision as not overburden one family member, the primary caregiver. The primary caregiver is the one who is most impacted the longer one lives with ADRD because the issues of care become more complex.

Long-Term Care

When addressing challenges that comes with care for one with dementia, long-term care becomes an area that families must investigate to determine what the future of the care recipient will entail. The elderly are at greatest risk of functional incapacity and use the most long-term care, although recipients of long-term care are both the old and the young. Long-term care is care provided over a length of time that can be continuous or occasional. It should be understood that long-term care is not meant to be an acute nature. Long-term care is different from acute not only in its length but also in the intensity and expected outcome of services. It is not provided to cure disease or prevent mortality (Gorin, 1997).

Long-term care is to assist with an individuals' self-care with a functional incapacity that may never be overcome. This functional incapacity or impairment might have been caused by any combination of physical, cognitive, emotional, and social factors (Kane & Kane, 1981). Therefore, the necessity for this kind of care cannot be foreseen with or without a chronic illness. The care is aimed at reducing the degree of functional impairment and enabling the person to realize the very best level of health and well-being by supporting the increase in their functional ability for as long as possible.

Functional ability is defined in several ways. The general areas of function are physical, cognitive, emotional, and social. Physical functioning is frequently viewed as a person's ability to perform activities of daily living and instrumental activities of daily living. Basic activities of daily living include ambulating, bathing, dressing, toileting, and eating; instrumental activities of daily living are those necessary to maintain independent living, such as preparing meals, shopping, housekeeping, telephoning, and managing finances.

The person may be (a) independent, (b) requiring mechanical assistance, (c) requiring

personal assistance, or (d) unable to do specific activities A person's ability to perform these functions is rated as either full, partial, minimal, or nil. It is affected by physical, mental, and social conditions and economic status. (Evashwick & Branch, 1987). Those using long-term care can be classified into three groups: the aged, nonelderly adults, and children. Traditionally, nonelderly adults and children needing this sort of care have been those with long-term disabilities as a result of (a) accidents such as spinal-cord injury, (b) heart attacks and strokes, (c) multiple sclerosis, (d) cerebral palsy, (e) developmental disabilities, and (f) chronic mental illness (Gorin, 1997).

Research of caregivers of kūpuna with age-related memory loss reports those with other chronic diseases being provided community care in Papakōlea. Additionally, more adults are beginning to be diagnosed with early onset of ADRD requiring care at an earlier age. The work in the community is guided by a practice design that allows for a whole-person approach mindful of culture and social needs of people using a community-based paradigm that identifies and builds on the reciprocal relationships of social, emotional and physical forces striving for balance. Leaders of Papakōlea have long recognized that socioeconomic forces directly affect the health of community members. Community-based services that include prevention education may be a promising strategy for addressing resident needs. Providing access to health and social services through community channels allow residents to receive assistance in a culturally sensitive manner embracing both traditional and western practices.

Community Investigator

Currently, as the Executive Director (ED) of Kula No Nā Po'e Hawai'i, there is a dual role at play with the educational role that takes precedence during the research process. As much as possible when embarking on this academic role as a student, there is an attempt to remove one's self as ED from the leadership role and consult other community leaders. Understanding the role of an African American visitor in the community of Papakōlea for more than 20+ years, embarking on this research project requires revisiting theories of power and subjectivity. This introspection will help with an understanding of one's own cultural biases and need for grounding while approaching colonization, oppression, and so

forth that are underlying factors in understanding how historical and cultural trauma impacts the researched.

There was concern about the relationship of the researcher with many of the caregivers who would agree to participate in the focus group and whether they would alter responses to impact what they thought was needed for the study. The focus groups helped to identify how caregiver knowledge, attitudes, and resources affect the care of kūpuna.

Papakōlea community facilitators trained by the University of Hawai'i, John A. Burns School of Medicine (JABSOM), Department of Native Hawaiian Health (DNHH) were tasked with conducting the focus groups based on the recommendation of the researcher's academic chair. There is no perfect discourse or theoretical framing to collect culturally appropriate information from stories due to the complexity of human relationships, across gender, culture and such. In the focus groups, there were three individuals responsible for independent content analysis. However, the representation is true based on our understanding of another's voice. Utilizing different approaches and theories, PEN-3 Model assisted in engaging with research participants but helped to shape various theories of social interaction. The socio-ecological theory and PEN-3 help to understand that changing landscape of the community and provides a glimpse of how it can be viewed within a culturally appropriate context.

Our worldview is influenced by the "isms" faced (e.g., racism, classism, sexism) which have become enmeshed in our cultural group identities on a daily basis. In conducting social analysis, all of the constructs are present in varying degrees in both the researched and the researcher. No one questions how much can be learned from our previous experiences and the experiences of others. What remains questionable is who can provide the most accurate presentation of another's experience.

Today, indigenous and people of color continue to be traumatized for the generations to come by the discrimination and racism displayed on a daily basis. This research will allow the opportunity to connect with this space and place within recapturing a sense of self and knowing as one looks at the Hawaiian experience from the outside in.

There is always questioning of why the Native Hawaiian population.

Understanding one's "Blackness" is crucial to being able to find a balance between and within the ethno cultural identities and experiences to be impacting one's attitude and beliefs. There is a need to be able to acknowledge and ground one's self in what part of the ancestral experiences are being carried forth and what we should separate ourselves from that will provide insight into the research approach. The discourse visits one's cultural experiences and understanding of a people's struggle along on this journey for a different type of intellectual stimulation and lens to view this research. Both groups, Native Hawaiians, and African Americans are deserving of health equity.

Native Hawaiians have a word "*kaona*" that is used in their mele (song) and hula (dance) that suggests there is an opposite or different meaning to the context of what is being sung or danced. Many of the underlying meanings may be suggestive or "*naughty*." Having a different meaning is what has been openly represented was is reminiscent of the dual or hidden meaning that was given to spirituals during slavery to guide them to freedom. Having been raised on the line of one of the many stops of the Underground Railroad, my ancestors continually provided stories of what our spirituals meant, how they guided the journey from south to north. As they ended the journey in Chicago Heights and East Chicago Heights, we are always to remember that our spirituals guided many to freedom with hidden meanings that kept many out of harm's way as journey ended for many too soon.

Many spirituals were said to have a hidden meaning that was coded for the slaves to provide direction during the escape north for freedom, a journey wrought with challenges. When addressing the issues of power and subjectivity in there exists an underlying theme of violence that eliminates the cause of health disparities because the conversation of resistance and resilience has been absent because we have not taken strength from the theoretical frameworks such PEN-3 or the socio-ecological theory that guides our strength as a people through communal numbers as we should. There always seem to be a concern when we visit the levels of engagement that does not isolate us one from another. Our

strength as people comes in our numbers, in our communities, when we unite to assist one another.

When addressing the issues of power and subjectivity in pursuit of health equity an underlying theme of violence should cause concern. Missing from the conversation is our strength as a collective nature, our experiences similar, we to our neighbors when our multi-generational communities strengthen us. Stripped of our voices, there are still volumes on the ancestral knowledge that we can call upon when one understands the resiliency and resistance inherent in the journey we assume.

Greater analysis of the theoretical and conceptual constructs lack addressing the merit of our unified existence. This includes understanding how the levels of happiness, resiliency, responsibility, and resistance is displayed by our strongest caregivers. This display helps to survive the many different challenges of seeing kūpuna through the stages of dying while they experience their grief. Caregivers who have given so much of themselves can only humble one and seems to give the impression resiliency is the greatest legacy from the experiences of cultural and historical trauma. Resilient people no matter what has inherited resiliency through their white benefactors.

In the conversation of power and subjectivity, daily a caregiver and kūpuna are engaged in the dwindling power of the kūpuna. This power is being dissected in the presence of others. Caregivers have responsibly to know how much they are needed to guide and support to ensure kūpuna retain the dignity they have earned. They deserve as they lose familiarity to with all they have known reciprocity in the expression of love. When exploring the complexities of ADRD, especially for our brothers and fathers, they fall to the overarching issues of social injustice, imprisonment, racism, masculinity, and death. The struggle of watching one being swept away mentally from the knowledge of ancestry kept apart from the culture, traditions, customs, and laws of the land require someone special who performs out of love.

Community Capacity. The current role of the researcher is to begin to explore in the academic journey as the role of the Community Investigator. Although still aware of

the guest role at play, the greater questions are what happens to a community that has agreed to participate in CBPR when the community investigator is part of the fabric of the community. During the focus group, the women with brothers discuss how in many ways the brothers seem to "check-out" on the care of the parent with ADRD, although no one believes there is an intention to dehumanize the parent, but for all who spoke of their brothers, it was the same. They had to be coerced at a time of desperation to engage, and it was still different.

Providing care and emotional support to a member of another gender was a significant challenge for both women and men. Women were perplexed as to what they might do to demonstrate dignity and respect for a relative's manhood. It is as if they felt that was the role of their brothers, to understand what was most needed as a man, by their fathers. They knew that in their matriarchal roles they would not be the ones that would be able to bring back dignity to a man. They would need to seek the help of a man. Ironically, their choice was their brothers who many times were reluctant to get involved. The man was once viewed heroically, is now unknown, lost ADRD and the impact it has on their existing relationship, be it father-daughter, husband-wife, sister-brother, makes one want to choose to intercede to make it better.

Explorations of the female caregivers provide a look at the unique matriarchal roles assumed by Native Hawaiian women. In their hand rests the importance of allowing a man to die with dignity. The gender roles and the ability to maneuver through various social systems and settings is apparent in the intricacies of ADRD and the various stages within communities to evoke change dismissing one from using their status and privilege of patriarchs and matriarchs. There is a duality of how caregivers and the ADRD patient are seen as their power is being eliminated. The caregivers can navigate through the cultural barriers with persistence and the support of the community, and other available resources to ensure that everyone meets his or her inevitable death with dignity, which is the catalyst for all that is to occur when looking at the socio-ecological theory or PEN-3 model.

The CBPR process designed correctly can create long-term systemic change placing

control of health outcomes in community hands. Research and community-university partnerships are meant to be an empowering process through which participants can increase their skills to achieve a balance between research and action; it involves systems development and local capacity building. The research study is expected to provide useful insight on community capacity and readiness to participate in research to improve the health and environmental issues of the community. Many caregivers are successful in their role as the ultimate protector. Although the impact the death of a mind can have on the community should be something that is taken into consideration.

The indestructible relationship between kūpuna and the community represents the key issue in understanding the inner conversion and ultimately his way of approaching death and dying. Death becomes a many-layered notion, and it does not merely take the form of biological but also that of social death and heroic death inner transformation and symbolic 'lesson' for others (Blanco & Vidal, 2014).

Caregivers need community and 'ohana support if they are to be successful in the role of the catalyst for changing an unjust and inequitable system. Although the men get most of the credit for redemption and transformation, we know that conceding to the wishes of the ADRD patient is sometimes what is needed.

In most instances there is a need to convey how one must understand the pain suffered by ADRD patients at the hand of someone be it family or foe, which now seems to give the impression that our greatest legacy from experience is we are all a resilient people, but rather that we are wrapped in the conversation of power and subjectivity, there must be a willingness to help all in the community. However, I would suggest as many others have, foundationally all the change throughout this narrative is presented through the tenacity of the legacy of the kūpuna of Papakōlea. The female caregivers, then and now, engaged and committed to supporting the families of the community. Social order dictates fate was sealed in the survival of the community before being made part of the Hawaiian Homes Commission Act of 1921

Recommendations. As a result of the work already being accomplished in

Papakōlea, findings of the study will be used to help with the implementation of Kula is developing a Kūpuna Community Care Network (KCCN) in Papakōlea, creating a trusted "one-stop shop" where elders and their caregivers can receive support, training, and access to critical health care services—helping kūpuna safely age in Papakōlea while maintaining independence at home, avoiding nursing home admission, reducing hospitalization, and minimizing social isolation. This project has policy implications because the community is seeking ways to be reimbursed by insurance companies for the efforts that support the aging population to age in place.

DFA Network is the U.S. licensee of the International Dementia Friends program, a global movement, developed by the Alzheimer's Society in the United Kingdom that is changing the way people think, act, and talk about dementia (Dementia Friendly America, 2015).

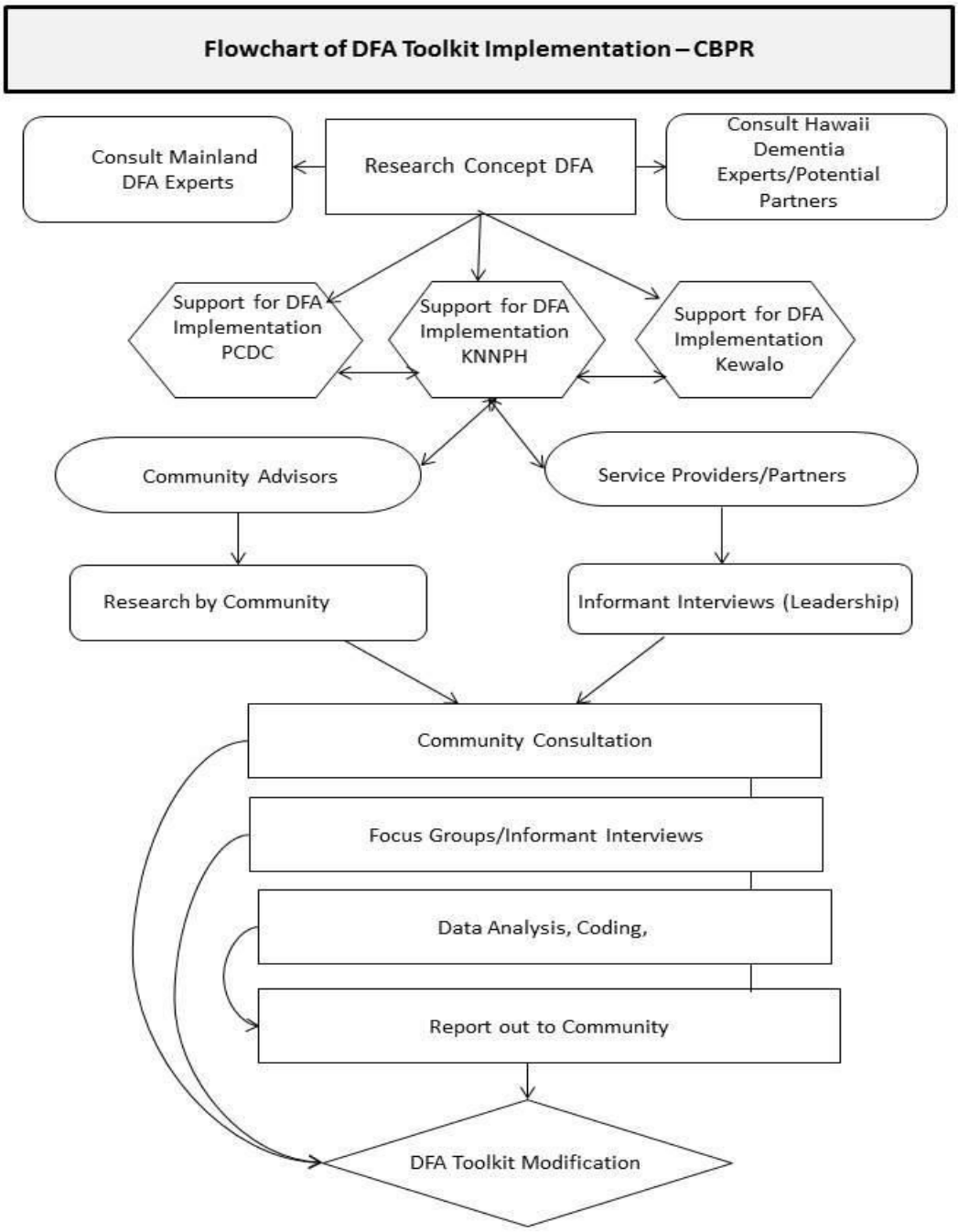

Figure 10. DFA Flowchart Papakōlea

The term 'dementia friendly communities' has emerged in recent years as policymakers and practitioners seek new ways to address the steady rise in numbers of people with dementia as the population ages. It reflects a growing movement to remind society that people with dementia have the same rights as everyone else to be treated with dignity and respect, to lead independent, autonomous lives and to continue to be active citizens in a society whose opinions are heard and acted upon (Mitchell, 2012).

Community involvement is needed to shape the intervention processes to align with research. This participation is achieved by forming partnerships with the health services, academic institutions, and community-based organizations. Papakōlea likened to other homestead communities are increasingly concerned about the well-being of their residents, seeing first-hand the ill effects of the health and economic conditions that plague them.

The purpose of this proposed study is to provide a synthesis of the elements and benefits of becoming part of the DFA network. Understanding community capacity and readiness are expected to provide useful insight on how the DFA toolkit can improve community care for the kūpuna and caregivers impacted by memory loss and other chronic disease. Understanding access to resources and behavior of community are essential elements to determining community capacity. The integration of all the mentioned elements is a prerequisite to forming partnerships to research as outlined in the DFA toolkit.

The significance of culturally tailored interventions reflects an intrinsic principle surrounding health disparities for racial and ethnic groups. Indeed, research has an enlightened modern inquiry that health services might need modification to gain the response that is crucial in the minority and underserved communities (Archibald, 2011). The research will help to understand, not only what type of respite is needed, but if current caregivers are accessing respite care.

Additionally, whether there is interest from survey respondents to help educate the community on the impact of dementia on Papakōlea, a community known for treasuring its

kūpuna. One of the ways this can be accomplished is by including caregiver feedback to culturally tailor the DFA toolkits to address their challenges with kūpuna with ADRD and other issues. The use of the DFA toolkits will be a valuable community asset as many caregivers encounter limited resources available to support their caregiving efforts.

KULA, in partnership with Kapiʻolani Community College, began training a cadre of passionate staff and volunteers to become certified Community Health Workers (CHW) in Papakōlea (when? month/year?). The CHW will serve as the frontline health workers because they have a close understanding of the community they serve. This trusting relationship enables them to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. Their role is to serve as a link to information and services, which will be critical in developing and implementing DFA. It is also anticipated that the results from this study will be used to inform kūpuna care within the homestead with the goal of providing safe, compassionate, and culturally appropriate care for kūpuna preferring to age in place with caregivers aided by DFA training and toolkits. This study provides an opportunity for Papakōlea caregivers to identify their concerns and information will be used to develop community-based interventions for caregivers of kūpuna wanting to age in place.

POLICY IMPLICATIONS

Many of the issues of aging warrant policy changes at the federal, state, and local levels. There are different policies specific to addressing Native Hawaiians health concerns which are not adequately addressing the issues of aging and long-term care, nor the projected increase in the population and the impact of ADRD on caregivers and families. Across levels, there does not seem to be adequate resources to focus on what is needed for kūpuna to safely age in place. When asked, Kūpuna feel there is a role for both family and government in their aging (Browne et al., 2014).

In 1988, the Native Hawaiian Health Care Improvement Act (NHHCIA) was legislated by the U.S. Congress to address improving the Native Hawaiian health status. The NHHCIA (1988) states (Civic Impulse, 2018):

> Native Hawaiians the high mortality rates and the incidence of disease that far exceed that of other populations in the United States upon the breakdown of the Hawaiian culture and belief systems, including traditional practices, that was brought by western settlement, and the influx of western diseases to which the native people of the Hawaiian Islands lacked immune systems. Further, Native Hawaiians predicate the high incidence of mental illness and emotional disorders in the Native Hawaiian population as evidence of the cultural isolation and alienation of the native peoples, in a statewide population in which they now only constitute only 20 percent.

Despite the NHHCIA, disparate health conditions exist, and only a modest improvement to the health status of this population has been achieved.

Since its inception, NHHCIA has authorized funding to Papa Ola Lokahi (POL) for the coordination of the health care programs and services provided through five recognized community-based Native Hawaiian Health Care Systems (NHHCS). Currently, POL oversees NHHCS, the Native Hawaiian Scholarship Program, and Community Health Outreach Workers. The NHHCS is:

- Ke Ola Mamo, Oahu
- Hoʻola Lahui Hawaiʻi, Kauaʻi
- Hui Malama Ola Na ʻOiwi, Hawaiʻi
- Hui No Ke Ola Pono, Maui
- Na Puʻuwai, Molokaʻi

Each NHHCS has health education and disease prevention programs that serve their island's unique health needs. Health services vary from system-to-system including primary health care, dental services, behavioral health services, transportation assistance and access

to traditional healing (Papa Ola Lokahi, 2014). Although the NHHCS have been in place since 1988, there has not been much improvement in the health status of Native Hawaiians. There have been approximately thirty years and millions of dollars allocated, and the health outcomes are still dismal for this population. The act authorizes POL to contract other community organizations to support NHHCS addressing the health care needs; however, the funding has remained limited to the five organizations. Research by Schölzel-Dorenbos et al. (2010) indicates a proposed hierarchy of needs of people with dementia to be considered between those living with dementia and their caregivers that have policy and practice implications that should be addressed (Pini et al., 2018). Culture's influence on elder health and family caregiving continues to be investigated to understand the influence of culture and the role of Hawaiian.

The reauthorized NHHCIA 1999 continues to provide federal level funds Papa Ola Lokahi and the five Native Hawaiian health care systems. Health seeing on the islands may need to be updated during its next reauthorization to be more focused on populations and frameworks of services to address various health issues. It is suggested the Native Hawaiian community begin to address policy initiatives targeted explicitly to Hawaiian Home Lands communities' utilizing a community-based approach with the Native Hawaiian Health Care Systems and other Ali'i trust organizations.

Additionally, a policy change to the Native Hawaiian Scholarship Program that would allow scholars to serve directly in the Homestead communities to meet their give-back commitments would be a different direction to a solution-focused approach, addressing the health issues on the ground. Individualized environments and individualized care are important elements in maintaining the quality of life for older people. Providing individualized care depends, however, on the availability of comprehensive, reliable, and valid ways of assessing what is important to individuals (Carpenter, Van Haitsma, Ruckdeschel, & Lawton, 2000).

When addressing long-term care for Native Hawaiians, there is only one kūpuna

housing facility on a homestead community and no authorized care homes or assisted living facilities for this population. Kulanakauhale Maluhia O Na Kūpuna in Waimanalo, Oahu, was built in 2002 to provide an opportunity for kūpuna of the lease waiting list to exchange their place on the lease wait-list for a rental unit. This 85-unit facility is the only kūpuna housing constructed on Hawaiian homelands (Office of Hawaiian Affairs, 2008).

However, the challenges encountered with the development of this facility has left DHHL unwilling to provide more kūpuna housing on Hawaiian Home Lands, as many cultural considerations were adequately addressed before occupancy. Similar to all older adults, quality care for Native Hawaiian kūpuna acknowledges their desire to remain in their own homes with an array of assistance from families, friends, and home and community-based services that honor and reflect their culture (Browne, Mokuau, & Braun, 2009).

Additionally, the rates of poverty suggest an inability of many homestead kūpuna to be easily placed in long-term care. The state of Hawaii has a shortage of nursing homes bed. Hawaii has a much lower supply of nursing home beds relative to its elderly population than other states. (Workforce Development Council, 2011). There is only one nursing home in the state designated for Native Hawaiians, Lunalilo Homes, and a 42-bed residential care facility which is quite costly.

Due to issues of economics, Lunalilo Home has non-Hawaiian residents. Recently, when trying to acquire a room for an ambulatory kūpuna diagnosed with ADRD, Kula staff was informed they would need a $55,000 deposit for the first two years of housing and a total spend-down of finances for Medicaid eligibility. This amount would be impossible for the family to provide at this time. However, it is no longer safe for the kūpuna to live alone, and there is no family or friends that can provide care as her disease progresses. There needs to be a policy that will begin to place care homes and assisted living facilities on Hawaiian Homesteads to support kūpuna and their caregivers.

Aging in place requires family participation. The mission of POL is to improve the

health status and well-being of Native Hawaiians and others by advocating for, initiating and maintaining culturally appropriate strategic actions aimed at improving the physical, mental and spiritual health of Native Hawaiians and their ʻohana (families) and empowering them to determine their own destinies (Papa Ola Lokahi, 2014). The ecological and system theory models are used to assist in framing the impacts of the environment on "aging in place" and the use of various support systems as the demand for services increases.

The research will continue to play a critical role in addressing the disparate social and health outcomes and improve the access and delivery of services to Native Hawaiian elders when combined with policy implementation. In 2013 the 20-year health study on Native Hawaiians and Pacific Islanders report to legislative committees at the state capitol from researchers from the John A. Burns School of Medicine highlighted despite the improvement in lifespans since the 1970's Native Hawaiians, and Pacific Islanders die earlier than other residents. The big three killers are diabetes, obesity and heart disease (Blair, 2013). These killers exist among cohorts born after 1965, the baby boomers, expected to have a daunting cost impact on social systems partly due to their longevity. The need for studies on social, health, and economic disparities and the effectiveness of culturally responsible solutions to the problems of the aged populations will continue (Browne, Mokuau & Braun, 1998).

Native Hawaiians have a disproportionate improvement in healthcare outcomes. One example of this is that because risk factors commonly associated with heart disease are prevalent among Native Hawaiians (Aluli, 1991), the supposition is that these high levels of heart disease and associated risk factors among Hawaiians reflect a limited awareness of and limited participation in prevention and treatment services. However, low participation in health care services does not necessarily suggest that Hawaiians do not care about their health. Instead, it likely suggests that the health care system has failed to provide services in ways that are accessible and meet the need of this population (Mokuau, Hughes, and Tsark, 1995).

When addressing policy, they should include a more equitable approach to addressing health disparities by creating a process to support grassroots initiatives which have not been done. One could ascertain that funding may have limited the ability to partner at various levels. However, of greater concern would be the inability to build upon the strengths that run throughout the Hawaiian community, the relationship of ʻohana to the community needed when addressing issues of aging such as ADRD and other concerns. In the way that the Hokule'a voyage showed how Hawaiians and others could learn, work together and confidently accomplishing their goals by utilizing traditional ways, Hawaiians need support and need to work together to reach their destination of wellness. (Hope & Hope, 2003).

Each reauthorization of the NICA becomes more difficult because the health data does not suggest meaningful improvement in health status for Native Hawaiians. This suggests that there needs to be a change in the approach of service provision and allocation of resources. Each of the policy recommendations can stand independent of the other although all combined would strengthen the approach of addressing Native Hawaiian health disparities and issues of aging for a geographically designated segment of this population, Hawaiian homesteaders throughout the State of Hawaii.

A few years ago the Council for Native Hawaiian Advancement (CNHA), Sovereign Council Hawaiian Homestead Assembly (SCHHA) and the Association for Hawaiian Civic clubs added promotion of health to its political agenda. Therefore, hypothetically addressing changes to the NHHCIA could have the support of some of the more influential Hawaiian organizations and may be needed in the current political climate around health disparities and improvements. One must understand, recommending a policy change to redirect resources that already exist versus adding a new dimension of funding for long-term care for this population could have an impact on preparing for the increase in aging and ADRD for Native Hawaiians.

Vulnerable communities like Hawaiian Homesteads can be empowered to address

determinants of health relevant to them. It is the responsibility of all to help ensure the survival and betterment of at-risk populations such as Native Hawaiians. Encouraging and supporting the voices of homesteaders about their most prevailing needs and allow health resources to be directly received by them to address their concerns will allow services to be addressed the community level. There is a mistrust of research in many indigenous communities resulting from past research atrocities brokering an active relationship remains challenging. Therefore, as these relationships continue to be built, there is a need for community-academic partnerships to remain equitable. Most communities do not want to feel dependent on outside entities to understand and address the needs of their residents without their input.

Three policy criteria were selected due to the population in which the problem is identified, nature of the problem, and the larger context in which the problem exists. The recommendations being made are from lessons learned while addressing health disparities in Papakōlea. The downside of this approach is that it could be a greater divide between Hawaiians on Homesteaders, those on the waitlist, and not on the land because they do not meet the blood quantum.

Policy Recommendations. Changes to the NHHCIA policies to target an additional level of Native Hawaiians to include providing services specifically to reach homestead communities as outside of the NHHCS population being serviced. The changes recommended were based on the evaluative criteria of effectiveness, political acceptability, and cultural appropriateness are:

- Developing Community based health services on Hawaiian Home Lands
- Native Hawaiian Scholar to provide services at the community level
- Community-driven partnerships with University Centers of Excellence to address aging

In 2010, the NHHCIA was again reauthorized for a ten-year period within the Patient Protection and Affordable Care Act (P.L. 111.148). The reauthorized act is within the

provisions of the Indian Health Care legislation. Under the section addressing the Native Hawaiian Health Care Systems (42 USC 11705) an additional "service to be provided" is inserted addressing the relationship between "health and education" (Civic Impulse, 2018).

A viable policy recommendation is to add DHHL as a recipient of a portion of the allocated funds for distribution to Hawaiian Homestead organizations providing community-based health services. Approximately 4 percent (30,855) of Hawai`i's total native Hawaiian population lives on Hawaiian Home Lands. An additional 7% are waitlisted (State of Hawai'i Data Book, 2010). As Hawaiian Homestead community organizations continue to work to address the social and health disparities, there is continued concern that the HHCA has no policies for native Hawaiians living on Hawaiian homelands to address the social determinants of health. Health Care Policy is needed for homestead communities.

The HHCA was to support self-sufficiency fully and the self-determination of native Hawaiians, however, DHHL has no contingencies made for Native Hawaiians living on Hawaiian home lands to address their disparate health conditions and social determinants of health in their administration of the HHCA. Addressing mortality and health concerns requires innovative approaches to prevent and control the impact of chronic disease.

However, there have been limited health programs or self-sufficiency initiatives implemented by DHHL. The community of Papakōlea has been successful in addressing the health disparities at the community level. Over the years, several organizations have offered limited healthcare services to the people of Papakōlea; however, no organization was ever able to sustain a meaningful existence within the community. Most programs have subsided as funding diminished.

The Bureau of Public Health regulations that require the service hours of scholars be met through a Federally Qualified Health Center (FQHC) or one of the five Native Hawaiian Health Systems to include service in Native Hawaiian Home Land communities. In 2004, Ke Ola Mamo (KOM) collaborated with Kula on behalf of the Papakōlea community and expanded services to the people. Ke Ola Mamo provides medical, dental and enabling

services to individuals' island-wide, particularly those who are uninsured or underinsured, with an emphasis on the Native Hawaiian population.

At that time, there was concern that Native Hawaiians were not adequately served through the healthcare systems. One way in which one could begin to measure the impact on healthcare service delivery was to have the kauka work directly in the community, developing a relationship with residents who would then be transitioned over a period to Dr. Jurek's private practice. Dr. Jurek was the first community physician to work out of the community center providing house calls to residents. As Kula began to pursue this concept, it was learned that the Bureau of Public Health regulations require the service hours of scholars be met through a Federally Qualified Health Center (FQHC) or one of the five Native Hawaiian Health Systems, of which KOM is one.

The community could not qualify to become an FQHC because the numbers accessing health services were lower than the regulations would require, and due to its geographic location, would not be considered medically underserved. Instead, the idea was presented to KOM, and they wrote a grant to hire Dr. Jurek as their first medical director. Although the number of services hours allocated to Papakōlea decreased from the time of the original conception until the signing of the MOA by more than half, the program was beneficial to both entities. An unanticipated outcome to the initial vision stems from the fact that Dr. Jurek had been led to believe that by acquiring a private practice, she could meet her hours by serving the Papakōlea community in her practice, unfortunately, and that was not the case.

However, despite the challenges she faced working as both KOM's Medical Director and in her private practice, Dr. Jurek found her experiences in Papakōlea to be both challenging and rewarding. As a result of the work with Dr. Jurek, considerations were made to have the Native Hawaiian Center of Excellence and the Center for Native and Pacific Health Disparities Research (the Center) located in the Department of Native Hawaiian Health (DNHH) at the John A. Burns School of Medicine. University of Hawai'i at

Mānoa added to the NHHCIA be allocated funds that will be used directly to benefit Hawaiian Homesteaders and other Native Hawaiians became another policy recommendation that was discussed.

Supporting policies that increase the capacities of communities' is one of the ways to successfully address health disparities and issues of aging for Native Hawaiians. Community history and community values are essential elements of capacity for community engagement. Capacity is seen as both a means and an end towards greater program effectiveness and sustainability. Communities differ from one another in many ways including resources, political climates, challenges, and strengths, not to mention size and diversity (Waller & Flewelling, 2007). Continued community engagement is highly recommended to shape the successful health intervention. This is achieved by forming partnerships between the health services, academic institutions, and community-based organizations.

There is a need for equitable access to all levels of government and policies impacting the diverse populations of Hawaii. Hawaii's political climate and diverse population require a different approach to facilitate changes that will address the inability of its people to support meaningful change through the legislative process without causing more profound divisions among the various people groups as the aging population increases. The political systems in this State continue to be plagued with challenges that stem from the status quo power structures that ignore historical inequities suffered by the host culture and other Pacific Peoples. Historically, Native Hawaiians, the host culture, have been among the most underserved in the Hawaiian Islands. The inequities are driven by government funding still make access to culturally grounded policies a challenge. Barriers that limit political access and adequate funding streams to address social determinants of health need to be eliminated.

Implementation of any policy and planning can be very devastating when social justice is not achieved. In Hawaii, the implementation of policy-making structures can be

complicated because Hawaii consists of many nationalities and policymakers must consider all of these factors when making and implementing policy. Because of the difference in the cultural values and the incoming of different people, the implementation needs to address the scale of changes that happen time to time (White House AAPI, 2014). Critics will warn against taking from one group to provide benefit to another and how it would negatively affect the social systems. There is an inherent ideological issue that should dismiss supporting people with systems that they cannot support or contribute to because they are unfairly seen as burdens on society (Kim & Casado, 2017). One must consider policy designed to advance compelling justice principles that include safeguard of island interests. The other mechanism states that government regulations must get followed by all equally.

Implementation is the process in which policy is actualized into practice, but it is essential to be mindful of gaps in the implementation process. The challenges of creating a policy that impacts community planning are the inability to ensure that policies are adapted to provide a safeguard for people. The goals of an institution that supports social policy implementation should be to promote policies that address government and civil society equally. The drivers for the success of the policy are that proper check and balance must be maintained. The concept of shaping academia to participate in addressing disparities in such a way that it will provide the benefit not only to the government but also the public sector by transforming new mind-sets will help convene ideas that challenge the status quo. The information that will be generated from the academic arena can be beneficial for the old boy network who have supported the lack of evolving principles related to public services and the civil society.

The applications of policies should include the support from the government. It is crucial to understand the means of achieving the targets, and on the other hand, it is critical there be a clear set of instructions provided by policy so that proper implications can be made. There continues to be a lack of parity many social services offerings for kūpuna and caregivers. However, as we explore the intent of government interventions, social policy

should not be structured as an economic instrument. Current policymakers politicize human challenges, and the systems that have been designed have tried to take on too many things. With that in mind, all we see is a shift from public to private and vice-versa, because none of the systems is designed to eliminate any of the situations that people face. We uphold the poor, illness, and other social ills with services. There is never a concentrated move to eliminate these situations.

As we look at the issues of aging there must be an elimination of the imbalances within the system and the needs of the people which requires continued exploration to modify the broken social systems when needed. There continues to be a lack of parity in so many social services offerings available. However, as one explores the of intent government interventions, social policy should not be structured as an economic instrument. The question of who has been harmed seems to be very relevant today. In the attempt to avoid the haves from unfairly affecting the 'have-nots,' it is possible through policy to address inequalities in social status through aging issues. The problems that can be foreseen when addressing some of the most significant challenges is how new policies influence social service delivery.

IMPLICATIONS FOR SOCIAL WORK PRACTICE AND SOCIAL WELFARE RESEARCH

Social justice and health equity are the signature values of social work and social welfare policy and research (National Association of Social Workers, 2010) first; there are policy implications for looking at the means to address the disparate health conditions of a vulnerable population, especially Pacific Islanders in the State of Hawai'i. Native Hawaiians and other indigenous and minority populations continue to produce alarming health statistics social work and social welfare need to remain vigilant and active in efforts to ensure accessible, affordable, and acceptable care for all.

Findings from this study compel further research, policy, and services that address family leave and benefits of the elderly as the conversation of changing the structure of benefits for the elderly through Social Security being categorized as an entitlement under

the current administration versus a benefit that has been paid for through years of work. Service innovations are important but require evidence of their efficacy. As of result of this research, social workers will conduct an intervention of a support group as requested by the participants of the focus group. Additionally, there are also implications for Social Work and Social Welfare practice.

This study highlights the needs of Native Hawaiian caregivers of a kūpuna with dementia needing and healthcare coverage 1) to adequately meet the needs of kūpuna presenting signs of memory loss needing home care coverage and 2) to alleviate stress

and burnout of primary and supporting caregivers with the implementation of adequate family leave when necessary. Health disparities are preventable differences in the burden of disease, injury, violence, or in opportunities to achieve optimal health as experienced by socially disadvantaged racial, ethnic, and other population groups, and communities (Centers for Disease Control and Prevention, 2013).

This research has determined there is a need for culturally tailored interventions and when the community has the capacity and readiness to participate in programs such as the DFA network. Membership in the network provides tools to support engaging the caregivers and kūpuna of the Hawaiian homestead community in understanding what is needed to address the growing need for resources and additional support for family caregivers.

Second, relevancy is seen when looking at approaches to community empowerment becoming increasingly more relevant to social work because it is premised on a strengths-based, an ecological perspective promoting building community capacity with CBPR. Third, adding to literature with relevant findings from research that focused on Native Hawaiians, as a way to strengthen marginalized populations addressing issues most important to them while promoting social justice is increasing in social welfare.

Furthermore, this research will begin to inform policy and practice initially at the community level, and the will be shared at the State level with other homestead leaders. There are limited investigations from a strengths perspective on Native Hawaiian communities. Indigenous place-based resilience requires understanding the traditions and sustained relationships with the land. Relationships are embedded in the land (McGuire-Kishebakabaykwe, 2012). This type of research is important to the field because many Hawaiian service agencies and grassroots organizations have limited knowledge and resources to address the increase in aging populations projected over the next few decades and the impact of Alzheimer's and dementia on families. This work recognizes that resilience is a "clustered" phenomenon that is not randomly distributed among individuals

in a society or community but occurs in groups of people located in a web of meaningful relationships.

The individual, family unit, community, and broader environment are interconnected, and factors from each realm contribute to processes that can counter stress and adversity. As the community of Papakōlea continues to include social workers in the work they are doing to address the issues of health equity their perspective is shifting towards an emphasis on collective processes, strengths, and assets (Richardson, 2002).

Therefore, this study has significant value for both Native Hawaiians, social welfare, and future work in the community on behalf of caregivers and kūpuna. In Hawai'i, the implementation of policy development may be complicated due to the State's diverse ethnic/racial composition and cultural preferences for health, caregiving, and other factors policymakers must consider when making and implementing policy.

Social workers are needed at every level to help facilitate understanding of aging in advocating for policy changes that impact kūpuna. Advocating to address the needs of the community is necessary for meaningful systemic change to eliminate barriers limit access and adequate funding to address socioeconomic disparities. There is a need for persistent advocacy of social justice issues so small community-based organizations with limited funding and resources can stay mission focused. Social welfare should assist in advocacy to provide a safeguard for people. The policy will only be useful if it is translated into specific actions and implemented.

Not all older adults are benefitting equally because of factors such as economic status, race, and gender (Centers for Disease Control and Prevention, 2013). The underlying premise presented is that more in-depth and better disease prevention happens through a community-based cultural model rather than a Western medical disease model. Community-based health and wellness initiatives that are culturally sensitive and community is driven in partnership with academia can assist in addressing

the prevailing health disparities for our community residents in our pursuit of health equity (Centers for Disease Control and Prevention, 2013). In Papakōlea, they continue to work closely with various partners addressing feedback received from the community by way of research to continue mentoring students and other community groups who want to adopt their program concepts for the advancement of the people of Hawai'i.

Through this study, the researcher hopes to inform future research carried out *in* and *with* communities on Hawaiian Home Lands and in Hawai'i. The research has yielded both positive and negative findings. Potential positive findings include the determination that community capacity can support this population in Papakōlea through current and future programs. Possible adverse findings include the determination that community capacity cannot be built because of leadership and organizational capacity in some of the community organization; and an absence of partnerships and resources available to address the concerns of this growing population.

The positive results could be utilized to investigate further additional information and methods that could be used to allow for, encourage, and enable communities to build further program offerings to support caregivers and increase organizational capacity to address the issues of aging. The negative results could help program staff and community leaders learn from and correct any mistakes and flaws in the current and future program design and implementation. Both qualitative and quantitative results derived from this study has provided suggestions for future community support can be viewed as opportunities to meet other communities' needs.

The nature of the focus group allowed study participants to explain why and how certain resources were available or unavailable and the impact to their caregiving. Focus group participants offered recommendations for participation in DFA; their desire to immediately begin support groups and education, however, program developers will still need to obtain from participants' how they would like to be supported and where they would like to begin.

In some instances, social welfare research has been conducted to effect change in the pursuit of social justice. The challenges of indigenous research when combined with the issues of spatial practices still have implications to question the validity of research practices and what it means to the researched people. This all speaks to power constructs. The selected methodology opens up explorations of the many facets to be revealed and understood by the individual and community. As community-based participatory research achieves greater acceptance within the research community, it becomes essential for the field to engage in the science of discovery and to learn how CBPR pathways work to promote new capacities, system changes, and health outcomes, both to generate stability for the field and to enhance the collective ability to have an impact on health status and health equity (Minkler & Wallerstein, 2002).

Continued disparities in health and other conditions have caused researchers to take a different approach to research in communities. Now, researchers are beginning to understand the need for cultural safety when entering certain communities. Cultural safety is a strengths-based construct which aims to subvert unequal power relations, honor diverse ways of knowing in community-specific contexts, and acknowledge community as the arbiter of 'how' safety is actualized (Ka'opua, Tamang, Dillard, & Kekauoha, 2017).

Locally, "communities populated by individuals with unique demographic and clinical profiles have been the target of institutional researchers for many years. Historically, these researchers approached a community, such as Waianae (on Oahu, HI), with a research question, beneficial intervention, or another valuable project that was implemented for a couple of years and then discontinued as funding waned. This resulted in hard feelings among community residents – left feeling used and abandoned. (Oneha & Beckham, 2004).

There continues to be needed an increase of researchers with research principles that do not approach studies from what communities' lack instead by their strengths to

obtain what is needed. As a construct, cultural safety integrates concepts of cultural humility and cultural competence, which similarly focus on the responsibility of providers to engage cultural differences in respectful ways (Ka'opua, et al., 2017). Sharing what is learned in Papakōlea will give voice to the work of their ancestors honoring the vision and legacy to pass forward by using research methods that honor and respect indigenous cultures.

A relationship with "critical" community leaders has been useful as they have assisted in approaching the residents for participation. There were minimal challenges to data collection as it was done properly, acknowledging the community as owners of all data collected, which is required when researching Papakōlea. Despite these many limitations, there is interest in, and value to a descriptive study of perceptions of caregivers specific to homesteads; added to the conversation was the understanding of implications of the succession of lease status in caring for kūpuna. The past and current work of Papakōlea in addressing health for its members will allow participants to share in the manner that is comfortable to capture the type of information that is needed. The study caring for kūpuna with memory loss and their caregivers in its broadest conceptualization is intended to inform other NH Homesteads in the State of Hawai'i of what is required to become a Dementia Friendly Community.

Residents continue to understand that Papakōlea is an extraordinary place that families will fight to protect. Papakōlea has the benefit of having many community organizations working for the advancement of the people of the community and for generations to come. These community organizations support a variety of programs focusing on youth empowerment and development, community mobilization and participation, cultural activities, and health and wellness. Programs such as these are crucial to the community's well-being.

Connection with the community and traditional Hawaiian values of laulima (working together) with less of a focus on individualism is a strength to the development

of this community. Showing reverence for shared cultural traditions and values and identifying with others in the community because of this shared history gives Papakōlea residents something larger than the individual to identify with and a greater sense of belonging to their community. This will continue to strengthen individuals, as well the collective community of Papakōlea to support a resilient Native Hawaiian community for years to come.

Appendix A: Focus

Group Guide Interview Guide

Step 1: Welcome and Mahalo to the caregiver for agreeing to participate in the interview.

Aloha, mahalo for having decided to be interviewed today. I will explain what is shared will be good for me to understand what type of community care or support should be provided. As I mentioned that this interview should take about 1 hour, but I will not stop you if we go a little over time, however, for any reason if you want to cut it short, it will be okay.

You were asked to participate in this research study because you received you received or were provided services related to a loved one with a memory loss disorder. As you know, we are interested in ensuring our kūpuna can "age safely in place," not have to leave the community if possible and that Papakōlea is a Dementia Friendly Community. Do you have any questions about the reason I am interviewing you today? Before we get started, let's first go over the consent form for your participation today.

Step 2: Review Consent Form.

Step 3: Start the interview.

Turn on the audio recorder and video recorder on and begin the interview:

Make all the pleasantries before started, addressing kūpuna health, latest outing, etc. See how the family is and if you know of their interest speak to that. (Approx. 3 minutes)

Okay, first question:

What does dementia friendly community mean to you?

Probes-

- Can you tell me a success story as a caregiver?
- Is caregiving for someone with dementia like you thought it would be?
- Did you experience any problems?

Next question:

What type of services do you receive to support you as a caregiver? Is this different from what you expected?

Probes-

- Did anyone influence your participation?
- Who are the best individuals to help you get the help/services you need?
- Who are the members of your team?

What are some suggestions or ideas you may have that could help make your caregiving experience better?

Probes-

- What are community resources available to help kūpuna?
- Are there services you have seen others use that you think you could use?

Why do you think community kūpuna have a hard time asking for help?

Probes-

- What do you think caused you to ask for help/services in the community?
- Are there any environmental, social, economic, cultural, or individual difficulties that prevent you from aging in place?

Before we end this interview, are there any other suggestions or ideas you may have concerning community care for memory loss, e.g., Alzheimer's and dementia that we have not discussed?

Step 4: Close the interview.

Appendix B

Glossary of Terms

Aging in place - the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level (Centers for Disease Control and Prevention, 2014)

Alzheimer's disease - is a progressive *disease*, where dementia symptoms gradually worsen over some years. In its early stages, memory loss is mild, but with late-stage *Alzheimer's*, individuals lose the ability to carry on a conversation and respond to their environment (NIH National Institute on Aging, 2016).

CBPR – CBPR expands the potential for the translational sciences to develop, implement, and disseminate effective interventions across diverse communities through strategies to redress power imbalances; facilitate mutual benefit among the community and academic partners; and promote reciprocal knowledge translation, incorporating community theories into the research (Minkler and Wallerstein, 2004).

The fundamental characteristics of CBPR are (1) it is participatory; (2) it is co-operative, engaging community members and researchers in a joint process to which each contribute equally; (3) it is a co-learning process; (4) it involves systems development and local capacity building; (5) it is an empowering process through which participants can increase control over their lives; and, (6) it achieves a balance between research and action (Minkler & Wallerstein, 2008).

Community - A community is a group of individuals that share a common physical environment, resources, and services, as well as risks and threats. It is also a collective body that has boundaries (often geographic), internal and external feedbacks, and "a shared fate." Because this community is a complex physical and social system comprised of many subsystems" (Longstaff, Armstrong, Perrin, Parker, & Hidek, 2010).

Community – an endarkened feminist epistemology emphasize connectedness with the community through relations, language, and cultural ways of celebrating identities, including rituals to honor the living and on living. Within this context, research should become a participatory activity that involves the community and serves the ideals of the community (Chilisa, 2012).

Dementia - A syndrome due to disease of the brain, usually a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, language, and judgment. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied and occasionally preceded by, deterioration in emotional control, social behavior, or motivation (World Health Organization, 2014). This syndrome occurs in Alzheimer's disease, in cerebrovascular disease and other conditions primarily or secondarily affecting the brain (Herbert, 2001).

There are many of types of dementia:

Dementia from Parkinson's disease – is a decline in thinking and reasoning that develops in someone diagnosed with Parkinson's disease at least a year earlier. Common symptoms include changes in memory, concentration, and judgment (NIH National Institute on Aging, 2016).

Dementia with Lewy Bodies - Dementia with Lewy bodies (DLB) is a type of progressive dementia that leads to a decline in thinking, reasoning and independent function because of abnormal microscopic deposits that damage brain cells over time (NIH National Institute on Aging, 2016).

Frontotemporal dementia - (frontotemporal lobar degeneration) is an umbrella term for a diverse group of uncommon disorders that primarily affect the frontal and temporal lobes of the brain — the areas associated with personality, behavior, and language. Also known as Pick's disease, is a syndrome featuring shrinking of the frontal and temporal anterior lobes of the brain. The symptoms of frontotemporal dementia fall into two clinical patterns that involve either: (1) changes in behavior, or (2) problems with language (NIH National Institute on Aging, 2016).

Vascular Dementia – the second most common type of dementia is a decline in thinking skills caused by conditions that block or reduce blood flow to the brain, depriving brain cells of vital oxygen and nutrients (NIH National Institute on Aging, 2016).

Dementia Friendly Community - A dementia-friendly community is one in which it is possible for the greatest number of individuals to live a good life with dementia; where people with dementia are enabled to live as independently as possible and to continue to be part of their community, but at the same time are met with understanding and given support where necessary (Prior, 2012).

Dementia Literacy - Dementia literacy is defined as knowledge and beliefs regarding dementia that aid recognition, management, or prevention. The term was taken for mental health literacy (Low & Anstey, 2009).

Readiness –The degree of community mobilization and existing capacity, environmental and objective, to address a public health issue (Salsberg et al., 2008).

Sandwich Generation - Caregivers who find themselves *squeezed* in between caring for younger loved ones such as children, and their elder parents or other elder family members (Alzheimer's Association, 2016)

Social Capital - The features of social organization, such as networks, norms, and trust that facilitate coordination and cooperation for mutual benefits (Putnam, 1993).

Social-Ecological Theory - The ecological and system theory models focus on the individual, his or her situation, and the effect of other influences on the person in the environment. This socio-ecological approach recognizes that culture is not static; and that a myriad of factors has a direct effect on overall well-being. In general, the social-ecological approach takes a broad stance that views human behavior in a larger social, institutional, and environmental context and encourages a break from traditional disciplinary boundaries, and is sometimes referred to as a transdisciplinary or interdisciplinary in approach (Hiatt & Breen, 2008).

As a multi-layered model of interconnected domains, the socio-ecological perspective also incorporates a variety of concepts derived from systems theory such as interdependence, homeostasis, and feedback, to better understand the interaction between individuals and their environment (Stokols, 1996).

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